



Daghustani, Wid Hussain (2017) *Journeys of mothers of adolescents with autism in Bahrain and Saudi Arabia: issues of justice?* PhD thesis.

<http://theses.gla.ac.uk/8578/>

Copyright and moral rights for this work are retained by the author

A copy can be downloaded for personal non-commercial research or study, without prior permission or charge

This work cannot be reproduced or quoted extensively from without first obtaining permission in writing from the author

The content must not be changed in any way or sold commercially in any format or medium without the formal permission of the author

When referring to this work, full bibliographic details including the author, title, awarding institution and date of the thesis must be given

Enlighten:Theses
<http://theses.gla.ac.uk/>
theses@gla.ac.uk



University
of Glasgow | School of
Education

Journeys of Mothers of Adolescents with Autism in Bahrain and Saudi Arabia: Issues of Justice?

By

Wid Hussain Daghustani

MA Special Education (Autism)

**A Thesis submitted in Fulfilment of the Requirement for the Degree of
Doctor in Philosophy (PhD)**

**School of Education
College of Social Science
University of Glasgow
May, 2017**

The path towards this thesis has been circuitous. Only because of the strong, courageous and gentle soul of each mother who participated in this study, and who taught me that so much could be done with so little, has this work become a reality.

I dedicate this thesis to you all.

Abstract

Autism, a lifelong developmental disability¹, can have a significant impact on parents, particularly mothers who are often the primary care takers of their children in countries in which understanding of and resources for young people with autism are limited. This study explores the lives of mothers of adolescent sons with autism in Bahrain and Saudi Arabia. I focus on the issues that arise in a strictly sex segregated society, Saudi Arabia, and ask how living in such a culture affects the capacity of mothers to support and care, and to be helped to support and care, for their sons. I consider the experiences of these mothers in contrast with those of mothers from Bahrain which, though still a traditional society, has a more progressive approach towards women who fully participate in society and have almost the same rights as men, at least in law. In a country like Saudi Arabia, mothers struggle with the complexities of autism in a society that often treats them as inferior simply because of their sex. In Bahrain, even though mothers struggle with autism and a lack of support, the social and political structures of the country are different. Bahraini mothers, for example, do not have to contend with male guardianship laws or a prohibition on driving, both of which, I argue here, extensively affect their capacity to care for their sons.

In this thesis, I apply Nussbaum's Capability Approach to questions of social justice for mothers of adolescents with autism. The Capability Approach is an evaluative framework that assesses individuals' well-being, exploring what a person can actually do and be when given opportunity freedoms. In a just society, according to Nussbaum (2011), every individual is entitled to dignity and respect and should be provided with appropriate threshold levels of functioning in ten central human capabilities which include bodily integrity; senses imagination, and thought; emotions, and affiliation. By engaging in conversations with 17 mothers, 10 in Saudi Arabia and seven in Bahrain, this study starts to tell the stories of these seventeen mothers. In their own words², the mothers I interviewed share their journeys with autism, discuss available social support, both formal and informal, and refer to and sometimes explicitly describe the cultural norms and regulations they encounter.

To analyse the interview data, I use thematic analysis and Nussbaum's Capability Approach to explore mothers' experiences. While I acknowledge that this is a small-scale study and I make only limited claims to generalisability or representativeness, the results of

¹ I discuss terminology in Chapter One but this term is taken from the UK National Autistic Society definition at <http://www.autism.org.uk/about/what-is/asd.aspx>

² Translated from Arabic to English as explained in Chapter Four.

my analysis indicate a significant lack of support, both informal from husbands, families and friends, and formal from hospitals and schools. Most mothers experienced difficulties dealing with autism, physically and/or emotionally. With respect to the Capability Approach, most Saudi mothers reported capability failure, largely because of the marginalisation of those with autism and gender discrimination. These capabilities are compromised because Saudi mothers live under laws which, I claim, promote inequality and injustice. With major gender inequality, mothers in Saudi, I argue, suffer greatly and their capabilities are jeopardised. By contrast, my data indicates that Bahraini mothers' capability development is less inhibited by the social and political arrangements of their country than applies to women in Saudi Arabia. This study draws out the significant differences in the experiences of women in two countries that are geographically separated only by a bridge but whose norms and conventions are radically different. I argue that in order to promote social justice for women, it is important to see the situation through their eyes and to research their experiences in ways that allow a deep understanding of their struggles in their societies. I conclude that it is vital to acknowledge and value the roles of mothers caring for their children with autism within their communities, and to develop and ultimately implement policies that allow their own capabilities and those of their children to flourish.

Contents	Page
Abstract	iii
Contents	v
Appendices, Tables	ix
Acknowledgments	x
Author's declaration	xi

Chapter One: Introduction and Context

1.1	Introduction	1
1.2	Research Rationale	2
1.3	Background to the Research	4
1.4	Nussbaum's Capability Approach	6
1.5	Adaptive Preferences	13
1.6	Purpose of the Research and Pre-Research Expectations	15
1.7	Research Methodology	16
1.8	Research Questions	18
1.9	Research and Emotions	19
1.10	To Sum Up and Move Forward	21

Chapter Two: The Two Kingdoms: Saudi Arabia and Bahrain

2.1	Introduction	23
2.2	The Two Kingdoms, Saudi Arabia and Bahrain	23
	• Saudi Arabia, the Beginning	25
	• Women in Saudi Arabia and Bahrain	28
	• A Woman's Right to Education in Saudi Arabia and Bahrain	29
	• Employment of Women, Saudi Arabia and Bahrain	31
	• The Male Guardianship Law	33
	• Other Restrictions on Saudi Women	35
	• Sex Segregation	36
	• Saudi Society and Change	38
	• Saudi and Bahrain Women's Achievements	41
	• Resistance to Change	45
	• Saudi Arabia and Bahrain, the Differences	48
2.3	To Sum Up and Move Forward	51

Chapter Three: Autism and Social Support

3.1	Introduction	56
3.2	Autism Spectrum Disorder (ASD)	56
	• Terminology	56
	• Definitions of Autism	58
	• Characteristics of Autism	64
	• Early Diagnosis and Intelligence	67
	• Causes of Autism	69
	• Adolescents with Autism	71
	• Autism and Stress	74
	• Social Support	76
3.3	Autism: Saudi Arabia and Bahrain	79
3.4	To Sum Up and Move Forward	81

Chapter Four: Research Methodology

4.1	Introduction	83
4.2	Research Objectives	84
4.3	Research Design	84
	• Qualitative Research and the Interpretive Approach	84
	• Good Research?	87
	• Interviews as a Research Tool	88
4.4	Research Questions	90
4.5	Ethical Considerations	93
	• Sensitive Research	97
4.6	Research Procedures	98
	• The Participants	98
	• Contacting Participants in Saudi Arabia	100
	• Contacting Participants in Bahrain	100
	• The Interviews	103
4.7	Data Analysis	105
	• Converting Conversations: Translation and Extract Transcription Process	105
	• Thematic Analysis	107
	• The Capability Approach	109
4.8	To Sum Up and Move Forward	109

Chapter Five: Autism - A Thematic Analysis

5.1	Introduction	110
5.2	Autism as a Broad Theme in Saudi Arabia and Bahrain	110
	• Phase One: Pre-diagnosis Phase Including Misdiagnosis	112
	○ Mothers' Awareness	112
	○ Mothers' Affective Responses	116
	○ Mothers' Interpretations of their Sons' Behaviours	117
	○ Mothers' Behavioural Responses	117
	○ The Misdiagnosis Phase	119
	• Phase Two: Immediately Following the Diagnosis of Autism	120
	○ Mothers' Awareness	120
	○ Mothers' Affective Responses	121
	○ Mothers' Behavioural Responses	123
	• Phase Three: Post Diagnosis Including Manifestations of Autism and Adolescence Phase	125
	○ Manifestations of Autism	125
	○ The Adolescence Phase	130
	▪ Mothers' Awareness	131
	▪ Mothers' Affective Responses	133
	▪ Mothers' Interpretations of Their Sons' Behaviour	135
	▪ Mothers' Behavioural Responses	135
5.3	Summary	137

Chapter Six: Social Support - A Thematic Analysis

6.1	Introduction to Social Support as a Broad Theme in Saudi Arabia and Bahrain	139
6.2	Social Support - Informal Social Support	141
	• Spouse Support	141
	○ Mothers' Affective Responses	149
	○ Mothers' Behavioural Responses	150
	• Family and Friends' Support	151
	○ Mothers' Affective Responses	154
	○ Mothers' Behavioural Responses	155
6.3	Social Support – Formal Social Support	156
	• Hospital Support	156
	• School and Autism Centre Support	160

• Other Institutions Support	165
• Societal Support	168
6.4 Summary	171
 Chapter Seven: The Capability Approach	
7.1 Introduction	173
7.2 The Participants and the Ten Central Human Capabilities	168
7.3 Summary	188
 Chapter Eight: Conclusions and Reflections	
8.1 Introduction	189
8.2 To Synthesise	190
8.3 Research Results and Discussion	194
• Mothers and Autism	194
• Mothers and Social Support	196
○ Informal Support	196
○ Formal Support	197
• The Stories of Mothers and the Capability Approach	198
• The Future	200
8.4 Challenges and Limitations of the Research	201
8.5 Future Work	204
8.6 Impact of the Thesis	205
8.7 Towards an Ending	209
 References	 211

Appendices

1.	Mothers' Stories in Saudi Arabia and Bahrain	235
2.	Sample Interview Notes and Extracts: Huda, a Saudi Mother	255
3.	Plain Language Statement	269
4.	Nussbaum's List of the Ten Central Human Capabilities	273
5.	Tables on Autism and Social Support (Sub-themes)	276

Tables

4.1	Data Themes	92
4.2	The Participants	99
5.1	Autism as a Broad Theme, Phases and Subthemes	112
6.1	Social Support as a Broad Theme	140

Acknowledgments

Foremost, I would like to offer gratitude to God Almighty for granting me the ability, the strength and the wisdom to finish this research.

It is an impossible task to acknowledge all the people who supported me throughout my studies in only few words, however I will try to extend my appreciation as best I can.

To Professor Nicki Hedge, who has been my source of inspiration. For her constant guidance and encouragement, her invaluable advice on both an academic and a personal level, without which this work would not have come to light, and for her unwavering support, I am truly grateful.

I would also like to express my sincere appreciation to my former supervisor and my friend Dr. Alison Mackenzie for her support during the first period of my study.

To my son, Aziz, your company and your patience during this long journey is what kept me going. To Tarik, the father of my son and my mentor, who remained willing to engage with my endless discussions. To you both, I am greatly indebted.

To my parents who helped me find and realise my potential, and gave their emotional and practical support during this study. For the time and effort of my father, driving me and waiting in the car during the interviews, which sometimes were three hours long, I struggle finding words of gratitude.

Without the financial support of the Arabian Gulf University, which offered me a scholarship to pursue my graduate studies, this research would not have been possible. I would also like to thank my friends Shaista, Hitesh and Rasha for their moral support which made my study and stay in Glasgow memorable. I am tremendously fortunate to have met you all.

Author's declaration

I declare that, except where explicit reference is made to the contribution of others, this dissertation is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Signature:

X 

Wid Hussain Daghurstani

Chapter One: Introduction and Context

The time will come when diligent research over long periods will bring to light things which now lie hidden. A single lifetime, even though entirely devoted to the sky, would not be enough for the investigation of so vast a subject.

Lucius Annaeus Seneca³

1.1 Introduction

As the Roman philosopher Seneca suggests in the above quote, and according to Georghiou (2015) research is to make a critical contribution to the development and growth of knowledge, though that research, no matter how long one engages in it, may never completely reveal what lies hidden. Be that as it may, research is not simply an academic activity; rather it can serve as a moral cause by enabling researchers to give voice to the voiceless, and to provide a repertoire of data to ensure the forward-looking, and progress of, knowledge (Field, 2011). By addressing key issues and unfolding valuable information, research may have an impact on society, improve the well-being of its members, and provide evidence needed to start a positive change. For me, the desire to hear the voices of the women in my birth-place, Saudi Arabia, and in my country of residence, Bahrain, and the experiences I gained in my Masters research, all motivated the current study which sought to reveal, if only in a slight way, the extent to which mothers of children with autism negotiate their worlds.

In this chapter, I initially provide a rationale explaining why I undertook the study and why I believe it to be important. I will, in addition, give a short description of the purpose of the research. Because I shall begin to use data from the study in this chapter I also outline a short narrative of my research and introduce the research methodology in order that readers are provided with a brief account of how I conducted the study and how I gathered the data. The chapter concludes with an outline of the entire thesis and a brief summary synthesising Chapter One.

³ <https://www.goodreads.com/work/quotes/13053194-naturales-quaestiones>

1.2 Research Rationale

While working on my Master's degree thesis, which focused on the sexual behaviour and the socio-sexual skills of adolescents with autism⁴, I found, to my surprise, how very few studies focused on adolescents with autism and the services they and their families receive in the Middle East. In Saudi Arabia, where that Masters study took place, both the study of adolescents with autism and research on their care seemed to be almost non-existent. Because Saudi Arabia remains a very conservative country, this may be because 'thorny' issues such as sex, sexuality, and disability, are frequently neglected and left un-researched. Discussion of the adolescent stages of any young person is mostly avoided since it is likely to raise complex issues, especially about sexual behaviour. These experiences formed my initial reason for deciding to continue working in a related area for my PhD.

Having a child is a turning point in anyone's life and most parents modify and change their life styles when they have a child. Having a disabled child is, perhaps, an even greater turning point in anyone's life and most parents modify and change their life style to a significant degree when they have a child with a disability. Autism is classified as a developmental disorder⁵ (Runswick-Cole et al., 2016), and a disability that is life-long with effects not only on the children concerned but also on their parents. Parenting a child with autism can cause a great deal of distress and anxiety among families whose children may experience many difficulties such as non-verbal communication, self-harm, obsessive and rigid routines and the ongoing need for care (see Chapter Three for stress of parents of individuals with autism). The common causes of stress range from a lack of support provided by formal agencies (Sanders & Morgan, 1997; Plant, 2011), to a lack of spousal support and a poor understanding of autism by the general public (Bitsika & Sharpley, 2004). Further, and of relevance to this study, since fathers are often less involved than mothers in the direct physical care of the child, mothers often assume the burden of responsibility for caring for the child, adding to the stress they often experience raising a child or children with autism (Cantu, 2010). In a country like Saudi Arabia, where women encounter many cultural, social and economic restrictions, access to support is particularly difficult (see Chapter Two for details on Saudi Arabia). In my Masters research, I had

⁴ I will be using the terms adolescents with autism, autism spectrum, autistic adolescents, ASD and autists to refer to autism.

⁵ I will explain the use of terms in Chapter Three.

observed the hardships and difficulties associated with autism and its care and the apparent lack of support available, especially for adolescents with autism and for their carers. I became particularly interested in the situation of mothers of autistic adolescents in Saudi Arabia and so began this study.

This research was, initially, intended to identify services available to mothers of adolescents with autism in order to compare what was available with mothers' actual needs. However, after early discussions, analysing the situation of women in Saudi Arabia, and reflecting on the care of adolescents with autism in greater depth, what started as research on social support became a matter of social justice. A mother who is expected to cope with the disability, with poor support, and with stress, also often encounters judgmental and unfair treatment, as I will discuss below and as my data will indicate. These mothers, as I will argue, confront the dual challenge of facing the demands of autism, and dealing with an unjust society. The idea was to address and understand autism, support and social issues from the mothers' points of view. While I was collecting the interview data from mothers in both Saudi Arabia and Bahrain, their experiences gave urgency to the need to raise issues of social justice. In societies where discrimination, gender hierarchy and unfair traditions are widespread and sustained by familial, religious and cultural practice (see Chapter Two), the question of social justice had to be addressed. Belonging to a certain culture or society can have a significant effect on a mother's well-being and her ability to care for her child. A child who is entitled to live a 'normal, proper' life despite his or her disabilities, as well as the child's mother, should surely be entitled to treatment, justice and access to resources that is as equal as that offered to all. My current research will help shed some light on mothers' situations in both Saudi Arabia and Bahrain. For this study, mothers share their stories and the issues they face being part of these societies, and I work towards identifying the support - from their point of view - that might help them to overcome the difficulties they encounter. Although this research is located in Saudi Arabia and Bahrain, and so I focus here on those particular contexts, it is important to note that many of the issues I highlight in this thesis pertain in many parts of the world. Although I restrict most of my discussion to the particular context and countries in which I collected my data and with which I am familiar, I do not want to suggest that my data or my commentary on it apply only to Bahrain and Saudi Arabia. Where appropriate I will refer to more universal trends and possibilities but I am mindful that I have only

conducted this research study in two countries and with a limited number of mothers of adolescent boys and young men.

1.3 Background to the Research

In Leininger's (1985, in Pandalangat, 2011, p.20) framework of culture, culture is defined as the learned, shared and transmitted values, beliefs, norms and life way practices of a particular group that guides thinking, decisions and actions in patterned ways. Culture, then, may include a broad range of things such as religion, language, gender, upbringing, ethnicity and life experience (Pandalangat, 2011). Arguably, people usually follow what is customary, rejecting anything new especially if it conflicts with their traditions. In a country like Saudi Arabia, people tend to follow traditions which, from their point of view, have a strong connection to religion, such as women being prohibited from driving, for example. Although there is no religious text to forbid women driving, people believe otherwise. Such an understanding of culture not only makes change difficult and, often, unacceptable, but it may also ensure that practices endure and form part of an individual's identity, in addition to promoting and maintaining unjust social practices such as gender inequality and sex segregation.

Gender inequality is a pervasive norm in Saudi society (see, for example, Rajkhan, 2014). Here women are mainly defined as wives, daughters and sisters, while men are the primary decision makers, even over the most personal of matters such as who to marry, or even whether girls should be educated. One of my participants, Nora, who had difficult pregnancies, conceived and had another child for the sake of her husband who insisted on having more children. Despite his lack of commitment to her Nora could not reject his request:⁶

My pregnancy was very complicated. I went through lots of pain and I could not move much. We have four children and I told my husband we have enough, but he insisted. Although I know he is not faithful to me, I couldn't say no to him. (Nora, SA)

Such an example demonstrates the power men often have over their wives, when even personal important decisions such as pregnancy are enforced upon women. Difficulties arising from gender inequality, lack of justice and unfair rules and regulations are made

⁶ I will be using a colon before long data extracts throughout the thesis, with SA referring to Saudi Arabia and B referring to Bahrain. All names have been changed.

worse without laws to protect women. Mothers of adolescents with autism in both Saudi and Bahrain must also endure the hardships and social stigma of the disorder. Since autism is a life-long disability, it can have a major effect on the well-being of individuals with autism as well as on the well-being of their families (Seltzer et al., 2001). Parenting a child on the autism spectrum raises many challenges, such as teaching the child social skills, developing the ability to communicate with others, preparing for his or her life as an adult, and the ability to integrate within society (Dyches et al., 2004). Rasha, one of my participants describes her experience thus:

I am the one fully responsible for my son, I feed him, bathe him, and I handle his tantrums. Yet I have no rights whatsoever. I tried to renew Sami's disability card⁷ but the employee refused to do it for me because I am a woman. I was at the office and the card was there in front of them, still they said no. His father needed to be there. (Rasha, SA)

Rasha's story exemplifies many of the problems women confront. These women are, often, the sole care providers and they may, and in Saudi Arabia did, have limited rights and experienced discrimination and exclusionary practices based on their sex. I will discuss these issues in greater detail in Chapters Five, Six and Seven and, in the following chapter, I will outline the historical, geographical, political and cultural context of my study with reference to Saudi Arabia and Bahrain and in relation to social justice and the position of women in both countries. Such content is important in providing an understanding of the societies in which this study is situated, and in which the participants live, since it will clarify the practices, customs and traditions, the treatment of women, and, I argue, the lack of social justice.

I use the term social justice in this thesis largely following Martha Nussbaum (2002, 2003) and in order to address issues of gender equality and how a just society ought to treat all of its citizens, including women, the disabled and the carers of the disabled. In Nussbaum's Capability Approach, what she describes as a partial theory of justice, all individuals should be treated equally regardless of their gender and with respect to their entitlement to opportunities and access to resources. These entitlements, in this approach to social justice, will not, of course, be precisely the same for every individual for, at certain times in anyone's life we might need greater access to resources than at other times. So, too, disabled children and their carers might need access to greater and different resources from

⁷ Children with disability receive benefits from the government depending on the type of the disability they have, and to do so they need to apply for a disability card.

those required by others. However, on this account, capabilities go beyond resources and utility to ‘help us to construct a normative conception of social justice’ (Nussbaum, 2003, p.33) that requires a willingness to:

... make claims about fundamental entitlements that are to some extent independent of the preferences that people happen to have, preferences shaped, often, by unjust conditions. (Nussbaum, 2003, p.34)

Of particular importance in this thesis, Nussbaum (2003, p.36) argues that her Capabilities Approach is a preferable if partial theory of social justice insofar as it can ‘handle issues of care, issues that are fundamental to achieving sex equality’. Hence, throughout this thesis, it is Nussbaum’s Capabilities Approach and her list of ten central capabilities, that informs my work and that underpins my references to social justice which, in sum and to be extended later, provide ‘a set of basic entitlements without which no society can lay claim to justice’ (Nussbaum, 2003, p.36). While I do not, in this thesis, develop arguments about the Capabilities Approach versus any other tradition, including, for instance, social contract theory, I was drawn to this approach initially as Nussbaum is clear that care:

for children, the elderly, and the mentally and physically handicapped is a major part of the work that needs to be done in any society, and in many societies it is a source of great injustice. (Nussbaum, 2003, p.53)

I refer to social justice throughout the thesis, ultimately asking if the stories of the mothers in my study raise issues of justice. I believe they do but I develop this further particularly in Chapter Seven. For the moment, I will provide an explanation of the Capability Approach and include in this section Moller Okin’s related views on justice.

1.4 Nussbaum’s Capability Approach

The Capability Approach is an evaluative normative framework for assessing individuals’ well-being and society’s political and social arrangements and policies (Robeyns, 2003). Application of the approach also helps to theorise about basic social justice, and to ask questions that are fundamental to what a person can actually do and become when given opportunity freedoms. Opportunity freedoms are ‘created by a combination of personal abilities and the political, social, and economic environment’ (Nussbaum, 2011, p. 20), and such freedoms are affected by social policies (Nussbaum, 2006). According to Mahbub ul Haq:

The real wealth of a nation is its people. And the purpose of development is to create an enabling environment for people to enjoy long, healthy and creative lives. (cited in Nussbaum, 2011, p.1)

Such a claim illustrates the need for an approach that can evaluate people's well-being by addressing issues such as inequality, discrimination, and lack of justice, all issues that I shall claim, are evident in the stories of the mothers I interviewed for this study.

The Capability Approach was first developed by the economist Amartya Sen in the 1980s, and was further developed by the philosopher Martha Nussbaum (Bhattacharya, 2010). Unlike Nussbaum's version of the approach, Sen does not include a list of capabilities, the concept of threshold level of functioning or the emphasis on human dignity. The basic core of the Capability Approach, according to Nussbaum (2006), is that each individual is entitled to dignity and respect, and that she should be treated as an end in herself and not merely as a mean to another's end. Individuals should also be given the freedom to choose how to live a life that they will value. Such freedoms should be given to all individuals and so applies, as Sen states, to 'every person anywhere in the world, irrespective of citizenship, residence, race, class, caste community' (Sen, 2009, p. 355). As my data revealed, very few mothers actually have meaningful freedom to choose, and I suggest they are not accorded the dignity of being full citizens, at least in Saudi Arabia. The development of Nussbaum's ten central capabilities, which I will present shortly, is necessary to achieve social justice in any society in which individuals should have the freedom to live their lives in the way they value most provided with no harm caused to others. The Capability Approach, using the ten central capabilities, asks questions about people's health, their nourishment, the ability to have access to necessary resources such as health care, education, political participation, taking part in social activities, and emotional and bodily integrity. The approach, as Nussbaum states, is about enabling people 'to live full and creative lives, developing their potential and fashioning a meaningful existence commensurate with their real equal human dignity' (Nussbaum, 2011, p. 185). I explore whether the mothers in my study are enabled in these ways.

The Capability Approach is similar to the human rights approach but, unlike a human rights approach, will ask questions about how women and children fare in the private sphere of the home where many women are controlled and abused. What happens in the

home is often protected from legal critique and this is as true of the UK as it is of Saudi Arabia and Bahrain though women in the UK are in a better position, legally and socially, to claim their entitlement to be protected from harm. The Capability Approach is a framework for reducing inequalities and advancing the enjoyment of human rights, helping policy makers and programmers to:

effectively localise and target inequalities that are the result of social, economic, and cultural disparities, and makes a priority of reaching those with the greatest need. (Thomas et al., 2015, p.12)

To highlight the similarity across human rights and the Capability Approach, Nussbaum states:

The common ground between both approaches lies in the idea that all people have some core entitlements just by virtue of their humanity, and that is a basic duty of society to respect and support these entitlements. (Nussbaum, 2011, p. 62)

However, the human rights approach does not adequately address issues of gender, race, or disability, and neither does it adequately connect human rights to human dignity (Nussbaum, 2011). Further, Nussbaum's Capability Approach focuses on the relationship between human and other species, and acknowledges the equal rights of individuals with disabilities, unlike, necessarily, the human rights approach (Nussbaum, 2011). The Convention on the Right of Persons with Disabilities, the CRPD (2006) does, of course, look at persons as 'subjects' of rights, rather than as 'objects' of 'charity, medical treatment and social protection' (United Nations, 2006), an important and significant move towards changing attitudes and approaches to persons with disabilities. The CA views the principles enshrined in the CRPD and other human rights declarations, such as the Convention on the Rights of the Child (UNICEF, 2014), as needing supplementation because such conventions do not ask what people are able to be and to do. In other words, the CRPD is not an evaluative framework for well-being, but a statement of basic standards without which it is not possible for people to develop dignity.

To improve women's life means not only making them aware of the rights to which they are entitled and shedding light on the problems women face within a society, but also on helping women understand 'their worth and their capacities' (Nussbaum, 2006, p.13). As I will argue below, women may come to accept their position as natural, inevitable and innate, adapting their preferences to suit the conditions in which they live, and in order to

survive. Women should be entitled to equal access to services, support and resources, but, as I have argued and demonstrated in this thesis, this is not the case for many women. Giving women the opportunity to enjoy freedoms, to make valuable life plans that reflect their values, aspirations and dispositions will increase their self-esteem, helping them to be and do, giving them the choice to be productive members of their society. Surely, women's influence on any society is undeniable, and to restrict this influence is a barrier to positive change and development. Yet, women in Saudi Arabia live in a very restrictive society in which simply being able to travel alone or without a male guardian is not allowed, with the result that they are forced to be dependent on close male relatives or hired drivers to take them where they want or need to go. The situation for women in Bahrain is quite different though, like many women in Saudi Arabia, they too face challenges caring for children with autism and the gendered practices that are engendered in families.

Saudi Arabia is a country in which rights, rules and regulations are deeply influenced by beliefs about the natural and immutable roles of gender, and in which gendered restrictions begin in the family. In a just society, Moller Okin argues:

The structure and practices of families must afford women with the same opportunities as men to develop their capacities, and to be economically as well as physically secure. (Moller Okin, 1989, p.15)

With a significant gender imbalance, most women in Saudi Arabia have neither economic nor physical security without their male guardians. Saudi women, further, suffer from living in what I call a judgmental society since the rules are shaped around people's sense of how women should conform to a male standard of femininity that serves men's needs and aspirations rather than women's own needs and aspirations. This is 'ethically indefensible', as Moller Okin (1989, p.55) would argue because, on her account 'hierarchies of dominance and submission are not natural'. When a woman is not treated equally under the law, she simply falls victim to gender discrimination and obsolete traditions. Arguably, she is not treated as a person, but as mere means to another's end, usually the end of her husband or other male relatives. Like the Indian women in Nussbaum's (2000) account of women and human development, Saudi women, 'What they hope for, what they fear, what they love, and what they are able to do' (Nussbaum, 2000, p.31), are all shaped by the society in which they live – and by men's needs.

As a Saudi woman myself, I have an understanding of the requirements of justice and the complexity of the situation in which the well-being of a woman depends on the attitude of her male guardian. The amount of freedom she is given to pursue her education, to work and to have mobility all depend on the man being legally responsible for her. This value system is, of course, highly paternalistic. Men tell women what to do, claiming that they are promoting women's good. But they treat women as unequal under the law, as lacking 'Full civil capacity' (Nussbaum, 2000, p.52). Moreover, cultural norms arguably reinforce patriarchy. For example, once a woman becomes a mother in a country like Saudi Arabia she is expected to lose, at least to change, her own identity to the extent that people stop using her name and start calling her 'the mother of ...'. However, it is important to note that for most women and men the term 'the mother of...' signifies respect rather than a loss of identity. Additionally, in Saudi and Bahraini families women are usually the primary caretakers, undertaking work that, though extremely important, is often both unacknowledged and expected. Saudi mothers are expected to fully manage the household and they will be judged harshly if they fail to do so. That same society, however, may find an excuse for men not to be productive members in their families and I have shown how that is the experience of some of the mothers in this study. As Moller Okin states:

The family is the first place where we learn morals and ethics, and until there is justice within the family, women will not be able to gain equality in politics, at work, or in any other sphere. (Moller Okin 1989, p.4)

Of course, people vary in their needs, each person according to their physical, mental and emotional health and at different stages in their lives. In my study, women who are mothers and considered the primary caretakers of their adolescents with autism, have their own needs and desires. Yet, they are expected to be fully responsible for their sons, mostly because no one else is willing to provide help or support. As a result, many of the women in my study apparently came to ignore their own needs in order to provide care to those who need it, their adolescents with autism. In other words, they have adapted their preferences 'downwards' in order to care for their sons, preferring, for example, isolation to the humiliation of public stigma and ignorance. As Nussbaum (2006) suggests, issues of care are closely related to issues of gender justice and in this key area of women's lives, women do not experience social justice for they are not regarded as equal to men.

In a society in which men and women are not equal, the hardship of being a woman with the added demands of being the primary caregivers for sons with autism, makes women's lives even harder. Nussbaum argues that when women do not have the same rights as men, rights to education, rights to work and rights to mobility, even though they are fully responsible for house chores and raising children, their capabilities will be jeopardised. Women with little or no power, according to Nussbaum (2000), will need additional help in order to reach a decent level of capability, especially in traditional societies where women have few rights as in Saudi Arabia. Women's position in Bahrain, as I will explain in Chapter Two, is much better than in Saudi Arabia.

The Capabilities Approach 'directs us to examine real lives in their material and social settings' (Nussbaum, 2000, p. 71), and so, in my view, the Capability Approach is an appropriate approach that can be used to recognise and evaluate the issues that the women in my study, in both Saudi Arabia and Bahrain, confront. It focuses on, as Nussbaum states:

Human capabilities, that is, what people are actually able to do and to be – in a way informed by an intuitive idea of a life that is worthy of the dignity of the human being. (Nussbaum, 2000, p.5)

To use such an approach is not only to explore whether the mothers in the study are satisfied with what they have, but also whether they are able to live a fully functioning life with respect and dignity, to ask whether they can 'be citizens who have dignity and deserve to be treated with respect on a basis of equality with others' (Nussbaum, 2006, p.17).

Nonetheless, there are criticisms of the Capability Approach (CA) and these need to be acknowledged. For example, the CA is criticised for being too individualistic and for ignoring groups and social structures (Stewart, 2004). Yet, I argue that to focus on individuals is important because inequalities and injustices impact on individuals, who of course, make up groups and are part of the social structure. Although my participants share many characteristics, each mother has her own unique story, and she has needs which may not be the same as others. If we respect social justice, to address each mother's well-being is crucial. Another criticism is that the list of the ten capabilities is general and without due reference to context (Robeyns, 2003). However, Nussbaum counters this by saying that the list is general and abstract, and should therefore be made specific according to the culture of the society in which it is located (Nussbaum, 2000). For that reason, determining where

the threshold of the ten capabilities lies will depend on the development of the country. In Bahrain, for example, being legally permitted to drive over the age of 18 is open to everyone provided they satisfy the conditions of passing the driving test. As for Saudi Arabia, for example, a recent case of two Saudi women, Loujain al-Hathloul, 25 and Maysa al-Amoudi, 33 who defied the law and drove their cars were referred to the criminal court in Riyadh and sentenced to more than 70 days in custody (The Guardian, 2014)⁸. This is a basic threshold level of functioning. In Saudi Arabia, this threshold does not exist for women, at least not legally or publicly, though some women do try to drive – at some risk to themselves if they do. Further, public transport is underdeveloped in Saudi Arabia, which makes being able to drive critical. In Bahrain, women have this basic entitlement as they can drive without restriction. As I will demonstrate in Chapter Seven, the absence of this basic entitlement has significant implications for the realisation of a number of capabilities, most notably affiliation. To address the participants of this study, especially the Saudi mothers who live in an arguably unique society, I argue that a minimum threshold must be provided, and more just policies are to be implemented in Saudi law and norms.

Another criticism of the approach is from Alison Jaggar, who argues that the approach is neo-colonialist and does not take into consideration cultural differences because, Jaggar claims, Nussbaum rejects any ideas that do not support liberal policies (cited in Kleist, 2013). Yet Nussbaum has stated that the CA is ‘for each and every citizen, in each and every nation’ (Nussbaum, 2000, p.6), and that the list is ‘open ended and subject to revision’ (Nussbaum, 2003, p.37). As a researcher, I found Nussbaum’s approach beneficial for my study as it helped to reveal gender inequalities and social injustices amongst my participants, enabling me to ask how far are these mothers able to do and to be. Applying the CA and the ten capabilities was not an attempt to westernise Saudi or Bahraini societies, but was, rather, a method to address a lack of social justice that I would argue, following Nussbaum, should be a universal aim of societies. In any case, Nussbaum’s development of the ten central capabilities was informed by her research on poor women in India (see Nussbaum, 1999).

⁸ <https://www.theguardian.com/world/2014/dec/25/women-charged-saudi-arabia-driving-ban-terror-court>

A further feature of the CA is the extent to which women adapt their preferences to what they think they can achieve: being a mother, a wife, being modest and subservient, and adopting roles and attitudes that conform to what society thinks are suitable. To discuss this further, I turn now to a brief outline of adaptive preferences.

1.5 Adaptive Preferences

Adaptive preferences occur when:

People adjust their preferences to what they think they can achieve, and also to what their society tells them a suitable achievement is for someone like them. (Nussbaum, 2006, p.73)

Adaptive preferences represent not what people truly prefer, but what they have been ‘made to prefer’ (Teschl & Comim, 2005, cited in Khader, 2009, p.196). Saudi men are raised to believe they are the decision makers, and that they have the upper hand over their sisters, wives and daughters. With a lack of mobility and the male guardianship laws (as I will discuss in Chapter Two), Saudi women are forced to depend on men in most aspects of their lives, which can make them vulnerable emotionally, socially and economically. As an adaptive strategy, Saudi women learn to accept men’s unfair actions and advantages as an unavoidable fact of life. Accepting this allows them to live more peacefully and quietly than if they were to resist, and for some of the participants resisting patriarchal practices was not even an option. Nora, for example, is forced to live with an abusive husband and none of the Saudi women are allowed to drive, a state of affairs they accept as a normal fact of life.

To accept men’s lack of support and attribute it to a man’s nature creates and sustains the status quo for succeeding generations without, I would regard a sense of justice. Women relinquish their rights in order to seek a quiet, and conflict free existence, because they believe that to fight for a different way is futile. Another reason for acceptance, I suggest, is that many Saudi women do not understand that they have rights and entitlements. As Nussbaum writes of Vasanti, one of the Indian women in a similar situation to the participants in this study:

The idea that it was a violation of rights, of justice, and she herself had rights that were being violated She did not have these ideas at that

time, and many women all over the world still do not have them.

(Nussbaum, 2001, p. 69)

In other cases, women might not see such rules as unfair but, rather, as acceptable and honourable for it:

... is not uncommon for both men and woman to cherish the way Saudi women are honoured as a result of trading their rights for affluence and protection. (Al-Rasheed, 2013, p.23)

To live by traditions that deem and treat women as naturally inferior to men in Saudi Arabia is a necessity for acceptance in society and, as human beings, we are not eager to be alienated. A woman should serve her man to better his behaviour as the philosopher Jean-Jacques Rousseau⁹ said of Emile's partner:

As she was made to obey a being who is so imperfect, often so full of vices, and always so full of defects as man, she ought to learn early to endure even injustice and to bear a husband's wrongs without complaining. It is not for his sake, it is for her own, that she ought to be gentle. The bitterness and the stubbornness of women never do anything but increase their ills and the bad behaviour of their husbands. (in Moller Okin, 1989, p.33)

This aptly describes the plight of many women in Saudi Arabia. However, while the social and political arrangements of Saudi society are, in my view, unfair to women it would not be right to ignore the positive aspects of the culture.

Many mothers in my study suffered hardship yet found comfort in the support of their family members as this extract from Nora's story illustrates:

Even after my marriage, my father used to buy the groceries and bring them over to my house so that I did not feel like I was missing out on anything. When my sister in law used to go shopping, my father would give her money and ask her to buy stuff for my daughters and me, such as clothes, shoes and bags. (Nora, SA)

While her family are supportive, it is her father who has the means to support Nora. To raise Saudi women to be aware of their situation, we first need to respect their cultural

⁹ JJ Rousseau was a French philosopher, writer, and composer of the 18th century.

values but I suggest that, through education and access to resources, we can start to show how retrograde are many customs and traditions.

To address the position of women in both Saudi Arabia and Bahrain using the Capability Approach underlines their rights as citizens, their status as persons. It highlights their lack of social justice and takes into consideration the sensitivity of their local communities. While such an approach is unheard of in both countries, it could be used not only to raise the awareness of women's position, but also to acknowledge their hardships and suffering. To address the issues of justice, surely we cannot simply rely on mutually advantageous relationships, and what people can give their communities, but rather on what all humans need in order to live a proper, adequate life, regardless of their productivity. That is, surely justice demands 'a set of basic entitlements for all people' (Nussbaum, 2004, p.4). Hence the list of the ten capabilities, which should be secured to all citizens to accomplish a just society and a life filled with human dignity with all ten capabilities equally necessary. Yet, to implement the list successfully we need to take into consideration the cultural context and have enough knowledge about the historical, religious and traditional background of the society concerned (Nussbaum, 2011) and, as I will indicate in Chapter Two, I am very well aware of how challenging it is, and will be, to implement the CA and its capabilities in Saudi Arabia, and I return to this in my final Chapter. Although the list is general and can be implemented in all societies, Nussbaum emphasises that it is flexible and open-ended as a sign of respect for diversity. Having explained the Capability Approach, noted some criticism commonly levelled against it and outlined the concept of adaptive preferences, I will now turn to a brief account of the research methodology after outlining the main purpose of the research and the pre- research expectations.

1.6 Purpose of the Research and Pre-Research Expectations

The purpose of the study is to explore the journeys, the stories, of mothers who have adolescents with autism in both Saudi Arabia and Bahrain. I am a Saudi but have lived and worked in Bahrain. These are countries I know well; they are, in many respects, similar yet completely different (as I explain in Chapter Two). Bahrain is relatively open and liberal, while Saudi Arabia is deeply conservative. Women in Bahrain have legal equality with men, women in Saudi do not. The journeys of my participants were researched by gathering the stories of mothers' lives and situations in both countries. Issues such as the

nature of, and the difficulties associated with, autism, support, services, society and culture are considered and discussed. Ultimately, such a study might in some small way help to change attitudes in the Bahraini and/or Saudi Arabian societies with respect to adolescents with autism and their carers as these are a largely neglected group as a consequence of living in a traditional society that does not yet fully include children or adults with disabilities (I discuss this further below), or fully support them. In addition, and as I mentioned earlier and as noted by Seltzer et al. (2001) and Lasgaard et al. (2010), there are few studies that have focused on adolescents with autism and the well-being of their families. It is my hope that the current study will help address issues related to the needs of mothers of adolescents with autism, encourage similar research in the Middle East, and provide more insights into the struggle of women in the region. I suggest that to investigate the lives of mothers and their adolescents with autism is crucial, since having a just, fulfilling and conventional life is one of the major goals all should be able to look forward to achieving in a socially just world. I investigate these lives using thematic analysis (as explained in Chapters Five and Six), and Nussbaum's Capabilities Approach (as explained in Chapter Seven).

All the mothers interviewed in my research experienced many hardships in order to fulfil their responsibilities as caregivers. The interviews revealed the extent of gender inequality and misunderstanding of autism in both Saudi and Bahrain, and I shall draw on my data to illustrate and exemplify these claims. Again, while my data is drawn only from Saudi Arabia and Bahrain, many if not all of the challenges these mothers encounter are faced by others in different parts of the world. The data appears in italics¹⁰ and the actual methods and circumstances of the data collection and the study participants are outlined in Chapter Four but here, and in order to draw on my data immediately, next I provide a brief outline of the research methodology.

1.7 Research Methodology

The study sought to explore the journeys of mothers of adolescents with autism in Saudi Arabia and Bahrain, using an interpretive approach (as I explain in Chapter Four). The

¹⁰ When the extracts are less than 20 words I write them in italics in the text using single quotation marks, otherwise I write them in a separate paragraph without quotation marks.

names of mothers and their adolescents with autism have been changed to secure their privacy and anonymity. The following principle themes were explored:

1. The challenges mothers face with respect to the autism disorder such as the characteristics of the disorder, diagnosis, awareness of and services for autism.
2. The support mothers receive from informal resources such as spouse and family, and the more formal support provided by institutions such as hospitals and schools, and by doctors and teachers.
3. To understand the cultural and gender factors that determine and influence both Saudi and Bahraini societies, and their effects on mothers.

As explained more fully in Chapter Four, to reach the participants for this study, mothers of autistic adolescents aged 12 to 21, I contacted Autism Centres in both Saudi Arabia and Bahrain to explain and discuss the purpose of my study, and obtain contact information for potential participants. I contacted the mothers, explained to them in detail the purpose of my research and arranged for interviews. The majority of the interviews were conducted face-to-face (10 interviews across both countries), while the remaining interviews were conducted by 'phone (seven interviews across both countries). While the main objective of the study was originally to explore the support available for mother' of adolescents with autism in Saudi Arabia and Bahrain through their stories, I also considered their positions as women, and their struggles with unequal societies, believing these factors to be interrelated and to play a significant role in shaping the mothers' experiences, not least with respect to the obstacles they face. Before I started my data collection I came to the research with certain expectations and, in keeping with the approach adopted here in which I acknowledge my own positionality and am explicit about my own thinking (see Chapter Four), I note these below.

Based on my experience as a native of Saudi Arabia, as a lecturer in Intellectual Disability and Autism in the Arabian Gulf University, Bahrain, and as a result of my Masters research, as woman and a mother, I expected to find that the following three factors would have a significant influence on mothers' experiences. Namely:

1. Cultural norms and traditions.
2. Gender inequality.

3. A lack of support and services for mothers of adolescents with autism.

As I will show throughout, but especially in Chapters Five, Six and Seven, these expectations were well-founded. Generally, cultural norms and experiences make it harder for mothers to acquire the support they need, especially in Saudi Arabia since, as noted above, it is a very conservative society with issues such as sex segregation and male-guardianship law. For example, some mothers could not enrol their sons¹¹ in Autism Centres because they did not have the father's consent. Lack of mobility was also one of things that had a significant impact on mothers' abilities to provide care for their sons as, for example, they could not take them to schools or to hospitals when they needed to do so. Most mothers struggled with inadequate support both formal and informal. As for autism, most mothers found it difficult to deal with the disorder throughout all the three phases; pre-diagnosis, diagnosis and post-diagnosis phases (see Chapter Five). At the beginning of the stories, before a diagnosis of autism, most mothers were confused because they did not understand what was happening to their sons, and in many cases obtaining an accurate diagnosis was not easy. After the diagnosis, another dilemma started, in which mothers struggled with finding suitable Autism Centres and support for their sons. As an attempt to fully understand the mothers' experience with autism and support, I engaged in conversations with them, in which they shared with me their stories, their emotions and their struggles. These conversations focussed on my main research questions and these are outlined below.

1.8 Research Questions

The over-arching research question was: What do the stories of mothers of adolescents with autism tell us? That question was focussed on the following:

What do the stories of mothers of adolescents with autism tell us about their journeys (from pre-diagnosis to the future)?

with respect to:

- societal norms and traditions?
- support (from informal to formal support)?

and with regard to:

- justice
- Nussbaum's Capabilities Approach (CA)

¹¹ I explain, in Chapter Four, why my study involved interviews with the mothers of boys only.

- gender.

In order to work towards answers, I followed Gilbert's (2001) views that, as qualitative researchers:

... our goal is to see the world through someone else's eyes, using ourselves as a research instrument; it thus follows that we must experience our research 'both intellectually and emotionally'. (Gilbert, 2001, cited in Swift et al., 2009, p. 62)

As I sought to answer my research questions, I very soon realised that I was experiencing the study both intellectually and, in a very significant way, emotionally, and so I turn now to a brief discussion of research as an emotional activity.

1.9 Research and Emotions

Although it was a daunting task, I felt privileged that the mothers in my study agreed to talk to me about their hopes and fears. They gave me the opportunity to ensure that their voices were heard, to express their feelings and thoughts about their lived experiences with autism and the societies in which they were living. In the process of encouraging the mothers to be more forthcoming, to make them feel comfortable and to try and establish a relationship with them, I shared ideas, attitudes and some of my own personal experiences and I return to this in my discussion of ethical considerations in Chapter Four. Ellis states that:

We can view our emotional experience as a legitimate sociological object of study and focus on how we feel as researchers as a way of understanding and coping with what is going on emotionally in our research'. (Ellis, 1991, cited in Campbell, 2002, p. 26)

Although I was trying to be, to some extent, neutral while conducting this study, I found myself emotionally involved and came to find that feeling the mothers' pain was a way to build trust with them, which was an important part of the research. Therefore, while engaging in conversations with the mothers, either face-to-face or on the 'phone, I experienced their emotions of agony, loneliness, helplessness and sadness. I experienced these emotions not only in my personal interactions with the mothers, but also every time I listened to the recorded interviews. I come from the same culture as my participants and although I have lived through similar rules and regulations, this had not been enough for me to realise how difficult life could be for them. During this research, the mothers

shared their intimate and personal stories with regards to their journey with autism, their relationships and treatment by their spouses and their hurdles within what I argue is an unjust society.

Being a mother myself, listening to another mother hoping for her son's death before her own evoked strong reactions. Many mothers cried during the interviews, and it was very hard not to feel overwhelmed and emotionally drained. I often ended up in tears myself listening to their stories many times after that. Data collection, as I learned, can be an intense experience, especially if the topic that one has chosen has to do with stressful human experiences. The stories that the qualitative researcher obtains in interviews, Morse & Field (1995, p.78) explain, 'will be stories of intense suffering, social injustice, or other things that will shock the researcher'. I was shocked but I felt uncomfortable sharing my own emotions openly with the mothers. As a researcher I felt I had to behave in a professional way as much as I could and not burden my participants with my reactions. I had to manage both my participants' and my own emotions, to hold back during the interviews and cry afterwards. I apologised many times to the mothers for bringing back sad memories and discussing hurtful topics. I was emotionally and physically exhausted, with mixed feelings of anger towards the society, and sadness and powerlessness about the mothers' suffering. I also experienced feelings of guilt as I encouraged my participants to re-live their painful experiences and felt that I had abandoned them to their stress and grief. I discuss this in greater depth in the following chapters but it is important to note here that, despite, for example, becoming upset when they talked to me, the mothers in my study wanted to talk and, indeed, often thanked me for listening. Although I grew up in the same society, I did not expect others to live with such struggles and I was ill prepared to hear of their experiences. I visited places I did not know existed, where I saw absolute poverty and complete anguish. Meeting the mothers and interviewing them was a rich experience, and I learned a lot from their stories with autism, support and society. This study changed me a great deal. It has provided me with insight into other people's struggles, and I have become more sympathetic and less judgemental and I discuss this more in the final chapter of this thesis.

1.10 To Sum Up and Move Forward

In this chapter, I have outlined the research rationale, and explained how the research path shifted from simply addressing the available services for mothers of adolescents with autism to issues of social justice. The purpose and the background of the study was also explained and, in the next chapter, I will provide a brief history of Saudi Arabia and Bahrain and discuss the position of women in general including their education and employment. Further, I will discuss sex segregation, the male guardianship law and similarities and differences between both countries. In Chapter Three, I will provide an overview of autism, its characteristics, causes and definition. I will also discuss the adolescence stage of autism and its relationship with stress and social support. In Chapter Four, I will present the methodology, the research design and the research tools I used to collect data. Further, I will give an overview of the participants, the themes and sub-themes emerging from the data, and data analysis with respect to thematic analysis and Nussbaum's Capability Approach (CA). In Chapter Five, I will address the findings with respect to mothers' experiences with autism using thematic analysis and the themes and sub-themes from different phases of the mothers' lives from pre-diagnosis, 'diagnosis, and 'post-diagnosis'. In Chapter Six, I will present further findings with respect to mothers' experiences with social support, informal and formal, in both countries. In Chapter Seven, I will analyse the data using Nussbaum's Capability Approach, including an application of her ten central human capabilities to examine mothers' experiences with respect to autism and social support in both countries. The eighth and final chapter will offer a summary and an overview of the study, and will revisit the challenges mothers faced with respect to autism, support and their societies and offer recommendations for future research.

All chapters in the thesis are approximately an equal length except for Chapters Two and Six. In Chapter Two, while I offer a detailed historical, religious and social account of both countries, because of its arguably unique characteristics, Saudi Arabia will be discussed at greater length than Bahrain. In Chapter Six, I present the findings with respect to social support which includes informal support (spouses, families and friends), and formal support (hospitals, schools and other institutions). Although I thought about dividing Chapter Six into two chapters the data were so closely related that I decided to retain it as a long chapter. As for the mothers' stories, it was difficult to share everything they told me because of the length of the interviews. However, in an attempt to do justice to their experiences and stories, I have constructed a brief story for each mother and these can be found in Appendix One. Finally, it is important to reiterate the point that a number of the

issues and challenges raised here such as caring for children with autism (see Ludlow et al, 2012), support for parents of adolescents with autism (see Bromley et al, 2004) and gender inequalities (see Connell, 2003) apply to many countries as well as Saudi Arabia and Bahrain. However, it is to Saudi and Bahrain that I now turn as these were the countries in which my study was located.

Chapter Two: The Two Kingdoms - Saudi Arabia and Bahrain

We have been brainwashed under the banner of tradition and religion, and we have been convinced over the years that as women we are incapable, weak and emotional - that we are not qualified for political participation. The environment has changed, and we will not allow any group to belittle our capabilities and prevent us from exercising our deserved political rights.

Dr. Rola Dushti, cited in Fatany, 2007, p.58

2.1 Introduction

Dr. Rola, President of the Kuwaiti Economic Society, in the above quote describes the stereotypical view of women in the Gulf that they are ‘incapable, weak and emotional’, and unfit for ‘political participation’. This view is widespread and deep rooted, especially in Saudi Arabia. In Bahrain, however, attitudes to women are less prejudicial – they have many freedoms that Saudi women lack, such as freedom of movement and the right to participate in public life. Though the environment is changing in Saudi Arabia, change is slow. Yet I suggest that most of these changes are superficial and do not aim to ensure women’s genuine equality, and I will discuss this further in this chapter. I will focus on the history, culture and religion of Saudi Arabia and Bahrain. This discussion will raise issues of gender and inequality, ultimately issues of justice that feature prominently in later chapters of the thesis. This chapter concludes by returning to Dushti’s suggestion that the environment has changed. As I will have argued, however, Saudi women have many obstacles to overcome.

2.1 The Two Kingdoms - Saudi Arabia and Bahrain

The Kingdom of Saudi Arabia¹² is located in the southwest corner of Asia. It is at the crossroads of Europe, Asia and Africa and is the largest Arab State in Western Asia. By contrast, Bahrain, known officially as the Kingdom of Bahrain, is a small archipelago of 33 islands located near the western shores of the Arabian Gulf, of which the main and the

¹² I refer to the Kingdom of Saudi Arabia as, simply, ‘Saudi Arabia’, the ‘Saudi Kingdom’ and ‘Saudi’ on occasions throughout this thesis.

largest island is Bahrain. Bahrain was a British protectorate, unlike its neighbour Saudi Arabia, and so the Saudis were not exposed to foreign and modern ideas like the Bahrainis. Bahrain was a British colony until it gained independence from the United Kingdom in August 1971, and declared its constitution in December 1973. Being a British protectorate meant that Bahrain had been open to modernisation and foreign ideas and the people of Bahrain were influenced by the British lifestyle (Singh, 2013). By contrast, in the Jeddah¹³ treaty in 1932, Al-Saud made an agreement with the British that they would not interfere in the internal affairs of Saudi Arabia and, instead, that they would accept the authority of the Al-Saud family (Singh, 2013). Whereas Bahrain developed as a relatively open country, Saudi Arabia was not influenced by a foreign culture and so stayed as a close community with its own traditions and mores.

In September 1932, the Kingdom of Saudi Arabia was established by King Abdul-Aziz ibn Abdul-Rahman Al-Saud who named the country after his family. Although Arabic was already the dominant language and Islam was the dominant religion, they were formally declared as the official language and the official religion of the country when it was founded. Since practising other religions is not encouraged publicly, and only mosques are allowed to exist, the country lacks freedom of religion. Saudi consists of four main regions: Al-Hijaz where Makkah¹⁴ and Al-Madina¹⁵, the most two holy places in Islam are located; Najad where the city of Riyadh¹⁶, the capital of Saudi Arabia, is located; Asir the southern area, and the Eastern Province which has most of the country's oil reserves (Singh, 2013). According to the Saudi Central Department of Statistics and Information, the total Saudi population in 2013 was some 29,994,272 people, with a four percent annual growth rate. 80 percent of the population are under the age of 40, and 40 percent are under 15; and the country is about 900,000 square miles (Hamdan, 2005). By contrast, Bahrain is a smaller country with a much smaller population of approximately 1,234,571 with a growth rate of 1.2 percent in 2010 (Al-Obaidli, 2012). Although Islam is the religion of the state, and 84 percent of the total population are Muslims, Bahrain is a mixture of many cultures and

¹³ A port city on the Red Sea, which is a modern commercial hub.

¹⁴ A holy city in the western region, the birthplace of the Prophet Mohammad and the origin of Islam. It has the Grand Mosque where people come for Hajj and Ummrah and is usually known as Mecca in the UK.

¹⁵ Another holy city, 451.0 km from Makkah, to which the Prophet Mohammad and his believers immigrated after facing problems in Makkah, and now considered as another centre of Islam beside Makkah.

¹⁶ The capital of Saudi Arabia. It is situated in Najd in the centre of the Arabian Peninsula. Although it is considered multicultural due to many people who are based in Riyadh for work purposes, it is mostly a tribal society with strict cultural norms.

religions in which mosques, churches, and temples are allowed and people have the freedom to practice their religion (Al-Gharaibeh, 2011).

Although Bahrain is only 25 km away from Saudi Arabia and is connected by a bridge, the ‘King Fahd Causeway’, the two countries cannot be more different. The bridge was built to increase the bonds between both countries, and was opened to the public in November 1986. The King Fahd Causeway has had a major effect on the economic and the social status of Bahrain since it is the only crossing from the island. Many Saudis live on the island and commute from and to Saudi Arabia daily for work or educational purposes. Arguably, many Saudi families also use the bridge to visit Bahrain for entertainment reasons since sex segregation there is not an issue and families can enjoy their time together. Other restrictions in the Saudi Kingdom, such as film theatres, live music and alcohol, are also allowed in Bahrain, which encourages many Saudis to cross the bridge to experience such freedoms. One of my participants, Samia, a Lebanese mother who was living in Saudi Arabia because of her husband’s job, moved later to Bahrain in order to access a better Autism Centre and to avoid the issues with mobility and sex segregated schools in Saudi. So, they now live in Bahrain and her husband uses the causeway to commute daily for work. In the following section, I will outline the origins of Saudi Arabia as we know it today in order to indicate how the country came to have what, in my view, are restrictive and repressive traditions that make for an unjust society in which women are unequal to men under the Saudi law.

Saudi Arabia, the Beginning

What Dushti (cited in Fatany, 2007) referred to as the ‘brainwashing of women’ is still, arguably, the norm in Saudi Arabia as the state has failed to implement clear gender policies and rules to support women’s rights. Such unclear policies means the society fluctuates between restrictions on women and so-called liberalism (Al-Rasheed, 2013). According to Al-Rasheed, ‘Saudi women’s marginalisation is a function of a historical process in which religion was turned into a state religious nationalist ideology’ (Al-Rasheed, 2013, p.280). Importantly, the Kingdom of Saudi Arabia is widely known as a conservative country that follows a strict interpretation of the Islamic law, ‘Share’a’ and this requires some explanation.

In the eighteenth century, the Arabian Peninsula was not yet united under the Al-Saud family. Mohammad ibn Abdul-Wahhab (1703-1791), an Islamic scholar, started a reformist movement in Najd (in the centre of Saudi Arabia) to challenge the spread of what he considered to be ‘fads’ among Muslims in the country such as the glorification of saints, worship of many Gods (polytheism), worship of trees and tombs, and using graves to make entreaties to God (Al-‘Arniri, 2001). Since these were entrenched practices, Abdul-Wahhab met with resistance when he objected to their practices and this led him to form a pact in 1744 with Mohammad ibn Saud, the leader of the region at that time, to spread what he believed was the accurate version of ‘Share’a’ law (Al-Dakhil, 2007). Under the protection and with the support of Mohammad ibn Saud, Mohammad ibn Abdul-Wahhab was able to carry forward his movement and the first Saudi State was united under both the ruler and the Islamic scholar. Although the first Saudi state collapsed when attacked by the Ottoman Empire in 1818, the agreement between the two families has remained in place until today and it still constitutes the religious-political power in the country (Aart et al., 2012). Mohammad ibn Abdul-Wahhab’s name was used to create the term ‘Wahhabism’ which is defined as a movement that seeks to purify the Islamic religion although such a term was not used by him or his followers (Blanchard, 2008).

‘Wahhabism’ is a form of ‘Salafism’ a word that refers to the pious forefather ‘Al-Salaf Al-Saleh’. ‘Salafism’ means following the footsteps of the first Muslim, ‘Al-Salaf Al-Saleh’, in lifestyle, behaviour, worship of God, and, generally, in trying to closely imitate them in everything they did (Aart et al, 2012). The term ‘Wahhabism’ is also used as a reference to extremism and is claimed as the source of Saudi Arabia’s conservative rules and norms, such as the prohibition of women from driving and sex segregation (Al-‘Arniri, 2001; Blanchard, 2008). ‘Share’a’, as noted, is the law followed in Saudi Arabia and is based on four schools of jurisprudence: ‘Hanafi’, ‘Hanbali’, ‘Shafi’ and ‘Maliki’.

‘Wahhabism’ is not one of the four schools but is a reformist movement from the 17th century as I discussed above (Khan, 2013). Arguably, since it is not one of the four accepted schools of jurisprudence, it should not be part of ‘Share’a’ law. However, when Saudi Arabia was united under King Abdul-Aziz ibn Abdul-Rahman Al Saud, Wahhabi ideologies were used to create the rules of the country (Diemen, 2012). These rules were based on a combination of a strict interpretation of Islamic and tribal, customary laws which were widely supported at the time and which continue to determine Saudi society to

this day. Many of these rules were established to keep women under the authority of their male guardians. Nowadays, in the Kingdom of Saudi Arabia, it is claimed that the basic law is based on the Quran¹⁷ and the teaching of the Prophet Mohammad – peace be upon him¹⁸- ‘Sunna’¹⁹ which represents the constitution of the state and is considered the ultimate source of reference for the Saudi legal system. As Al-Farsy states:

In unifying the Arab States into one cohesive nation it was Islam, which, like a spinning wheel, wove the various Arab people together in one strong fabric. It was the tie of faith rather than anything else which enabled King Abdul-Aziz to found his kingdom. (Al-Farsy, 2009, p.21)

Islam certainly tied the people together in one fabric in Saudi Arabia. The space of freedom available to people is usually determined by social norms and regulations, where such regulations define the acceptable behaviour within a society, so that, for example women should cover their hair and/or within strict families, should be completely covered by wearing the Burqa²⁰. However, the state did not allow its women the freedoms Islam gave them and so, for example, things such as the ban on driving has no religious text to prohibit it, and I will return to this later in this chapter.

Though the cultural norms of the country may not have changed greatly, particularly with respect to women’s status, the economic and the social status of Saudi Arabia changed dramatically upon the discovery of oil in the 1930s (Hamdan, 2005) leading to educational, social, and political changes that impacted the social structure of the entire country (Al-Khateeb, 2007; Riedy, 2013). The oil boom brought many foreigners into the country along with their cultures and this exposed Saudi Arabia to a completely different way of life. With such a major change, one might have expected positive changes in the position of women. However, while Saudi society generally enjoyed a high standard of living, no attention was paid to gender equality and its role in social justice (Al-Rasheed, 2013). Instead, the government tried to implement a modernisation plan without changing the traditions and customs of the society. As Long states:

¹⁷ The holy book of Islam.

¹⁸ We utter ‘peace be upon him’ every time the prophet’s name is mentioned as a sign of respect. I shall follow this norm but, from now onwards, write ‘peace be upon him’ as a footnote to ease the flow of reading while still indicating my respect.

¹⁹ The teaching of the Prophet Mohammad – peace be upon him.

²⁰ A garment worn by women to cover their faces in public, also known as a ‘Neqab’.

From a cultural perspective, dealing with the cultural aspects of modernisation is probably the overriding challenge of Saudi society, and the cause of much of the stress which is witnessed in its younger generations. There is a growing call for social change to accompany economic and technological change, and maintaining an equilibrium between modernisation and a society based on Islamic values will continue to be the country's most pressing challenge in the twenty-first century. (Long, 2005, p.33)

Therefore, and following Long, the country struggles between striving for change and the power of traditions in which a gender hierarchy is still dominant. As I noted earlier, women's needs and freedoms are usually shaped by the demands of other people, almost always men, and I shall turn to this now.

Women in Saudi Arabia and Bahrain

During my research, the meetings with my participants revealed a gendered hierarchy and, on occasions and in my view, its cruelty and unfairness. Women in Saudi Arabia fall under the restrictions of culture and traditions, in addition to gender discrimination and an unequal social status that, as my data will demonstrate (see Chapters Five, Six and Seven), place a significant burden on many of them. According to the Global Gender Gap Report²¹, Saudi Arabia has a very high gender gap and ranks 129th out of 134 countries (Al-Rasheed, 2013). In a society where women have few rights, their well-being is often compromised by what I call unfair social norms and regulations. Where inequality of power between men and women is customary, many women tend to think of themselves as socially and morally less worthy than men, as well as accepting their unfair situation as a social, if not an immutable, fact. Many of the mothers I interviewed in this study do not acknowledge their current situation as negative, as one of agony or suffering. Rather they perceived it as their destiny. However, when women's rights are denied to them then they are often not given the opportunity to function equally and freely and this can prevent them from becoming politically and economically productive members of their society. While Saudi women are held back because of the country's traditions and mores, their Bahraini peers are more publicly active. Bahrain has a modern approach, in comparison to Saudi Arabia, and this empowers women and allows them to play equal roles to men in the development of the

²¹ The report measures the economic, political, education and health criteria, to allow a comparison between countries.

country (Al-Gharaibeh, 2011). Thus, Bahraini women have the ability to practise their freedom socially and politically within their society. By contrast, women in Saudi Arabia have been, and will no doubt continue to be, at best at the centre of debates and arguments about how Saudi Arabia is to move forward. To paraphrase Dushti (Fatany, 2007), the environment has not yet changed enough to enable and empower women to develop their capabilities and exercise their political rights. Despite the fact that many women are well educated and some are now actively demanding their rights, the law in Saudi Arabia, including that of male guardianship to be discussed later in the chapter, still promote gender inequality. Nonetheless, women's education can significantly impact on their capacity to demand their rights (Hoare, 2009), increasing their self-confidence, ambitions, and independence which could lead to a more equal society, as I will discuss in the following section.

A Woman's Right to Education in Saudi Arabia and Bahrain

A woman's right to education in Saudi Arabia was first discussed during the era of King Faisal ibn Abdul-Aziz Al Saud between 1964 and 1975, according to Al-Rasheed (2013). When King Faisal wanted to introduce girls' education to the country, he was faced with a complete rejection of the idea from the religious scholars, the 'Ulama'a', who had, and still have, foremost authority in the Kingdom. At that time, the 'Ulama'a' claimed that education would have a negative impact on Saudi Muslim families and would corrupt the morality of girls. King Faisal argued, by using quotes from the Holy book 'The Quran' and the teaching of 'Sunna' of the Prophet Mohammad²², to argue that girls, as much as boys, had the right to be educated, and that there was nothing in Islam that takes this right away from them. In the time of the Prophet Mohammad²³ women used to receive equal education and the Prophet himself used to teach both men and women, boys and girls. One of the Prophet's sayings is 'The seeking of knowledge is a duty incumbent on every Muslim, man and woman' (cited in Singh, 2013, p.171). However, many conservative families did not send their girls to school until the 'Ulama'a' confirmed that it was acceptable to do so (Hamdan, 2005). Therefore, and for many years, girls' education was run by religious committees, which were made up of male religious scholars to ensure that it remained within its purpose of making women good wives and mothers. It was not until 2003 that the government decided to merge girls' schools under the Ministry of Education

²² Peace be upon him.

²³ Peace be upon him.

(CEDAW Committee, 2007), reflecting a full acceptance of Saudi Arabian society of women's equal rights to education. However, the education of women can still be limited. Although a Saudi woman has the freedom to go to school, social norms and regulations often determine the type of job she might do so that it does not affect the household, as I will discuss later in the chapter.

As for education in Bahrain, it was one of the earliest countries in the region to encourage women's education, starting formal education for girls by opening the first public girls' school, 'Khadija Al-Kubra', in Al-Muharraq city in 1928 (Al-Obaidli, 2012). Today, in Bahrain, education for boys and girls is compulsory from the ages of 6 to 14 and the female literacy rate is 93.5 percent, the highest in the region (Worley, 2017). As for universities, Bahrain has no restrictions on their female students with respect of what subject they study, unlike Saudi which allows only male students to join any department they wish. It was not until 2007, for example, that women were allowed to study in departments of law in Saudi (Kelly, 2009). Other privileges with respect to education that men, but not women enjoy in Saudi, are flexible attendance times in universities and colleges. For example, in King Saud University in Riyadh, male students have the right to come and go as they please, while female students are not allowed to leave the university before midday regardless of whether they have lectures or not. Such restrictions are unheard of in Bahrain.

Education should enable the development of critical thought such that citizens can reflect on and question the country's political and social arrangements, as argued by Al-Gharaibeh (2011). It is possible that an aware woman in Saudi (or anywhere in the world) may not be satisfied with a state of affairs which results in inequality, very limited rights and a lack of social justice, by which I mean women's opportunities to do and to be from Nussbaum's Capability Approach perspective (see Chapter Seven). The women I interviewed who had only a high-school education²⁴ seemed to experience more hurdles and relatively less independence than those who were educated to university level. Nora, for example, a mother educated to high-school level, told me how few choices she had when her husband divorced her:

²⁴ High school finishes in Saudi Arabia at the age of 17 or 18, and education is not compulsory at all.

My husband hit me and divorced me, but I had to come back to him for the sake of my children and for Ahmad, my son with autism. I knew he would not take care of them and I had no place, no degree and no income to take care of my children on my own. (Nora, SA)

With no independent means, Nora had to return to an abusive and neglectful husband for the sake of her children. As I noted earlier, even though girls' education is often accepted by Saudi society, the kind of work she can do will be restricted by her role as wife and mother. Her responsibilities towards the household must come first and so I now outline the employment of women.

Employment of Women, Saudi Arabia and Bahrain

In Saudi culture, where the family has priority, what a woman can do is a shared decision by the family, but mostly by its male members. As Al-Hariri states (1986), 'the family in Saudi Arabia is a part of society which represents customs and habits and has a very strong structure' (cited in Singh, 2013, p.163). Some girls prefer to stay at home upon completion of their bachelor's degree since the family is considered to be more important than a career, especially as household chores are seen as a woman's responsibility. If Saudi women decide to work they can encounter many obstacles such as gender discrimination and little or no authority in relation to their position. As Hamdan explains (2005):

Women employees in Saudi Arabia do not have authority in any position and are inferior to men in both the private and the public spheres - even with men who often have fewer qualifications than their female counterparts. (Hamdan, 2005, in Bahkali, 2011, p.21)

So, regardless of women's level of education, they are still subordinate to men in the workplace. The type of work women can obtain is also a source of conflict in Saudi Arabia. For example, while society accepts that women may have jobs in education, it passes harsh judgment on women who work in occupations such as film making, photography, fashion design and the media, including acting and interviewing (Bahkali, 2011). Such restrictions may increase women's unemployment rates in the country and they certainly constrain women's choices. In 2008, the unemployment of women was about 24.9% with men's unemployment at 5.6% (Al-Rasheed, 2013). Recently, it was reported²⁵ that overall unemployment in Saudi is at 11.6% women's unemployment at 32.8% , the highest in the world, according to the International Monetary Fund, and

²⁵ <http://saudigazette.com.sa/article/153083/Unemployment-facts-and-figures>

excluding the 3.8 million women classified as ‘housewives’. Further, even if a job is socially acceptable, women still need written approval from their male guardians to accept any employment position and I will return to this guardianship law many times through this thesis.

When a woman is not employed, she is forced to be dependent on men, especially in a country like Saudi, which potentially increases male authority and power over her. One of my participants accepted a job in another city far away from her sons with autism because she had an unsupportive spouse (see Chapter Six) who often talked about having a second wife. So for financial security, Rana took the job but her husband made life difficult for her, as she explains:

When I first started my job in a different city, my husband was furious with me. After I left the house he would always call shouting and screaming saying: ‘Come back home and take care of your children’. Rana continued in tears ‘Since I started working in another city, my husband always asks me to quit my job and come back. It is not easy to find a governmental job these days, and I have achieved my dreams by doing what I am doing. Also, it makes me feel safe and secure - if something bad happens between me and my husband I can actually take care of myself and my children. Yet, my husband does not care - he does not see me outside the circle of being a wife and a mother. (Rana, SA)

Rana continued to describe why her husband was so set against her working away from home – to satisfy his own comfort and needs:

Most Saudi men are selfish, since the only thing that matters to them is their comfort. He says to me: ‘I feel comfortable when you stay with the children, when you are far away I am the one who has to do everything, I attend to their needs and stay up most of the nights. I want a house with a woman in it’. Sometimes I understand where he comes from, but he has a helper at home and a driver, also my oldest daughter helps a lot. I just do not want to leave my job! Just before I came to see you, we were discussing this topic, again he asked me to quit, and again I refused, and it was more of a fight than an argument. (Rana, SA)

By contrast, in Bahrain, women play a more significant economic and political role in the country (Al-Jishi, 2013). In 2000, the Business Women’s Society was established in Bahrain to promote the role of businesswomen in the country, and to encourage social and economic networks among them (Al-Obaidli, 2012). Shaikh Mohammed ibn Essa Al-Khalifa, of the Bahrain Economic Development Board (EDB), states that:

Bahraini women are vital in ensuring that we continue to improve the already attractive environment which enables business to operate

and compete effectively both in and from Bahrain. (Bahrain Factsheets, 2013, p.3)²⁶

As Shaikh Mohammed said, Bahraini women have a significant role to play in the development of the country and by 2002, women in Bahrain owned 30.6 percent of the country's businesses. 34.3 percent of the total work force is accounted for by women, a figure considered to be the highest in the Gulf countries (Al-Gharaibeh, 2011). The employment of women in both government and private sectors is also increasing. By 2009, the number of women employees in Bahrain had increased to 14467 women in the government sector and 14562 in the private sector (Karloak, 2012). The government also offered a number of incentive programmes to help women contribute to the economy by providing, for example, loans to help establish small businesses. As a result, women were granted 81 percent of the available loans (Bahrain Factsheets, 2013). In addition, Bahrain has many examples of successful women in high status educational jobs such as Sheikha Mariam bint Hassan Al Khalifa, the president of Bahrain University, and her vice-president, Dr. Jawaher Al-Modheki (Al-Gharaibeh, 2011).

Not only is the empowerment of women vital for social development in any country, but it also increases financial independence and decreases gender discrimination (Jayachandran, 2014). Women with equal access to financial resources and job opportunities have a positive effect on the development of their societies (Zukang, 2009). However, some social norms and regulations can deny women their basic rights, such as the male guardianship law in Saudi Arabia, which I will discuss next.

The Male Guardianship Law

In this section, I will only discuss Saudi Arabia since the guardianship law does not exist in Bahrain. The law of the male guardianship, 'Al-Mahrram' is, arguably, the most controversial and restrictive law among Saudi people. Regardless of a woman's age, education or qualifications, she must have a male guardian, which, I suggest, reduces women to the status of a dependent minor. A woman, whether she is single, divorced or a widow, is the responsibility of her father, brother or her son when he reaches 18. If none of these relatives are available, her uncle, grandfather, nephew or any other 'Mahrram' male relative, that is a relative she cannot marry, will be assigned as her guardian, her

²⁶ <http://www.bahrainedb.com/en/EDBDocuments/EDB-Women-in-Bahrain-May-2013.pdf>

‘protector’. Married women, of course, are under the protection of their husbands (Aart et al, 2012).

Many of my participants in Saudi suffered from the law of guardianship by being denied basic rights simply because their husbands were not supportive of their aspirations. For example, when Nora finally managed to find a school for her son, Ahmad, the school refused to accept Ahmad or look at his papers without his father’s presence. The same happened with Rasha as noted earlier when she was unable to renew her son’s disability card without his father present. The male guardian in Saudi Arabia has almost unlimited power over a woman as almost every essential choice or decision a woman can make must have the written consent of her husband or male guardian, whether that is to obtain an education, apply for a scholarship, have a career, or travel abroad (Offenhauer, 2005).

Rasha shares an example of her daughter’s thwarted ambitions:

We all are suffering, my daughters and me. My daughter got married just to get a scholarship since girls are not allowed to get a scholarship if they do not have a male guardian. None of my sons agreed to go with their sister, so she had to get married. Even though she was careful, she got pregnant with twins. After her girls were born, her husband changed his mind about travelling, and it would be hard for her to travel alone with two little girls so she did not go. All her friends went abroad to pursue their studies - she was accepted for the scholarship as well but did not manage to go! (Rasha, SA)

Not only do women need permission from their guardians for these essential areas of their lives, ‘Al-Mahrram’ also comes into force in government institutions and in renewing passports or collecting official documents. Women cannot take their new-born babies out of hospitals and the hospitals cannot issue birth certificates without the presence of the father. After I gave birth to my son, my husband went to collect the car while I was still in the hospital with my parents. I asked the nurse to get my son ready, but she said they do not have the authority to release the baby without his father’s presence. I tried to explain that his father was waiting for us outside but she apologised saying this was the rule. Until my husband returned, I could not leave the hospital with my son. Moreover, women cannot open bank accounts for their children or make any transactions without the consent of the husband or the father, and neither can they withdraw money from accounts even if they are the ones who deposit the money. In addition, women are not allowed to rent property in their names though they can buy property (CEDAW Committee, 2007). The guardianship

law, which puts enormous limitations on their rights and freedom, pervasively controls women in Saudi Arabia: women are not allowed to work, drive, or make their own life decisions simply because of their sex (Riedy, 2013). A quote by the Saudi activist, Wajeha Al-Huwaidar (2007), describes women's status with respect to the male guardianship law.

The ownership of a woman is passed from one man to another.

Ownership of the women is passed from the father or the brother to another man, the husband. The woman is merely a piece of merchandise, which is passed over to someone else - her guardian.

How do you recognise a maid or a slave? The decision making is out of her hands. All the decisions are made by the master. Women today are not allowed to make any kind of decision- not about, work, studies, leaving the house, or travelling. (cited in Hartley, 2016, p.1)

I can testify to Wajeha's description of women's situation and heard similar accounts during the interviews with my participants. Nora, for example, describes why her eldest daughter had to wait for two years before she could finally attend university.

Girls cannot be accepted in the university without their father's written permission. When my oldest daughter graduated from secondary school, my husband prevented her from attending university. She stayed home for two years doing nothing until her younger sister graduated, then they started going to university together. (Nora, SA)

Other Restrictions on Saudi Women

Further discrimination against women can be found in family law. If a Saudi woman marries a non-Saudi man, their children will only be allowed to apply for Saudi nationality when they reach the age of 18 and only then if they meet certain conditions. A Permanent Resident Permit will only be given if the applicant has lived 10 years continuously inside the Kingdom, has good behaviour, and no criminal record (Jawhar, 2012). While children of Saudi mothers are treated as foreigners and have to meet the above noted requirements, the children of a Saudi man and non-Saudi woman, on the other hand, are automatically granted Saudi citizenship at birth (CEDAW Committee, 2007).

Another act of injustice against women occurs in the court of law. Justice in court depends on the judge's personal interpretation of Islamic law 'Share'a' (Kelly, 2009). Women can

still, today, suffer from judges who choose to implement what they believe is an accurate interpretation of ‘Share’a’ law. In 2006, a happily married couple was forced to get a divorce. When the woman’s father, who had agreed to the marriage, passed away, her brother filed a petition to the local judge asking for his sister’s divorce on the grounds that her husband came from an inferior family, which affected the status and the reputation of the wife’s family. The judge agreed and the wife was divorced from her husband against her will in the court of law. Because she refused to obey the decision, the woman was sentenced to nine months in jail (CEDAW Committee, 2007). A further restrictive law in Saudi but not Bahrain is sex segregation, which I now discuss.

Sex Segregation

Unlike in Bahrain, sex segregation is strictly enforced in Saudi Arabia in order to prevent any opportunity for ‘intimacy’ and ‘informality’ (Aart et al., 2012). According to the conservative regime in Saudi, the mixing of sexes, ‘ikhtilat’, is forbidden in Islam because it encourages men and women to look at each other in indecent ways that can create feelings of desire. As a result, and in order to avoid spreading corruption in society, in many cases women are not allowed to leave their houses unless it is absolutely necessary. The absurdity of sex segregation can be seen in the call by a professor in Al-Imam Mohammad ibn Saud Islamic University in Riyadh to demolish and rebuild part of the Grand Mosque in the city of Makkah so that men and women would not have to mix with each other during worship (Aart et al., 2012). All mosques have separate sections for men and women, and have a closing time, except the Grand Mosque in Makkah. The Grand Mosque is one of the oldest mosques and was built before the time of the Prophet Mohammad²⁷ with a sacred status even before Islam. Similarly, a recent petition to the Ministry of Health signed by male doctors, Islamic scholars, ‘Sheiks’, and some female doctors, asked for hospitals to be sex segregated (Aart et al., 2012).

However, there are Islamic scholars such as Al-Gamidi who argue that ‘ikhtilat’ is not forbidden in Islam by any religious texts. Instead, there are many texts that indicate ‘ikhtilat’ is normal. He states:

The mixing of men and women was not at all forbidden by religious law, rather it was the normal practice during the time of the

²⁷ Peace be upon him.

Companions of the Prophet Mohammad'. (cited in Aart et al., 2012, p.18)

Al-Gamidi also criticised the conservative regime for using weak and contested religious texts to support their points of view (Meijer, 2010, P.20). Sex segregation has many impacts on women's position in the country. It results in women having their own private places in almost every public institution in which women are employed. There are women's sections in banks, in some hospitals, universities, schools and charitable organisations. In restaurants and cafes there are family and single men's sections, and women are only allowed to eat in family sections. In public universities when a male teacher is giving a lecture, he interacts with his female students using closed circuit television²⁸. Additionally, in public conferences and lectures, women are seated in separate areas from men. With many believing in the ideology of sex segregation, they do not accept mixed workplaces which results in giving male guardians the right to prevent their wives, daughters, or sisters from working in mixed sex environments. Although most work places within the Saudi Kingdom are segregated, some companies allow men and women to work together but in separate offices. However, there are places where the sexes share the same workplace such as in hospitals, bank head offices, and some private sector companies. We can also see the sexes mixing in places such as shopping malls, and at some events such as books fairs and exhibitions (Fatany, 2007; Meijer, 2010). But, as for the Saudi government, they reinforce sex segregation by providing spaces in which only women work as this is the most socially acceptable way for many people (Le Renard, 2008).

Even where women are employed, in working environments such as universities and schools, all the major decisions are made by administrations which are controlled by men. For example, in all-women universities, women in both teaching and administrative positions have limited authority as all the main decisions come from the male administrators so the real job for a woman is to implement the decisions made by the male manager (Hamdan, 2005; Fatany, 2007).

²⁸ The male teacher would be sitting in separate room with a camera that transmit his voice/image with the women students in another room seeing/hearing him through a screen.

Sex segregation had a major impact on the participants of this study. Mothers were denied access to their sons' schools and Autism Centres as Rana, for example, demonstrates:

I was worried about the sudden change in Yazeed's behaviour towards school. I tried many times to get my husband to go and check but he wouldn't. He always says to me, 'I will go tomorrow or I don't have time'. I wish I could go myself and see what is happening to my son. All I could do was to write a letter to Yazeed's teacher and send it with the driver. But I still did not receive any reply. (Rana, SA)

Nora experienced a similar situation:

The teacher asked the driver not to pick Ahmad up anymore, so I called the school and talked to the teacher and told him that Ahmad is very excited to come to school, and he waits outside the house every morning waiting for the driver to pick him up. But the teacher yelled at me and said, 'We do not talk to women, have your husband come and talk to us' and he hung up the telephone. Then I tried so hard with Ahmad's father to go to school and talk to them but he would not go. So Ahmad is back at home again, and I do not know what to do. (Nora, SA)

Fatima also struggled with her son's sex segregated school:

Once I went to my son's school to talk to the class supervisor, the door attendant went in and called the teacher, and then the teacher came out and told me the supervisor will be with me in 5 minutes. I waited in the heat for more than an hour and no one came to talk to me. The door attendant refused to go in again! So I had to take a taxi and went back home. (Fatima, SA)

These women are powerless to do anything without the consent and cooperation of their husbands and when that is not forthcoming, mother and child are disadvantaged. As I have suggested, women in Saudi Arabia face many obstacles, and I argue that Saudi society puts anachronistic and unnecessary restrictions on them. However, there have been changes in recent years (Jawhar, 2014), some of which can be found in the political, entertainment and educational sectors and I turn to these now.

Saudi Society and Change

In the political arena, The National Dialogue, 'Al-Hewar Al-watani', was launched in 2003 by King Abdul-Allah ibn Abdul-Aziz, the Crown Prince at the time, to encourage discussion and debate on important issues concerning Saudi society and including international relations, education in the kingdom, and women's issues (Meijer, 2010). Noticeably, a number of women were appointed to take part in this dialogue and were

given opportunities to discuss women-related issues and to express their opinions (Chaudhry, 2014). The Consultant Council ‘Majlis Al-Shora’, a male only body established in the 1990s to give advice to the King, appointed 30 women in 2013, 20 percent of the whole council (Fatany, 2007). The first female Deputy Minister of Education for Girls Affairs, Norah Al-Faiz, was appointed by King Abdul-Allah ibn Abdul-Aziz in 2009 (Fatany, 2007).

One of the main changes in the education sector is The King Abdul-Allah Scholarships Programmes (KASP) which began in 2005, and supports the education of over 100,000 Saudi students overseas in about 46 countries (Taylor & Albasri, 2014). The aims of the programme are to promote intellectual developmental, meet the needs of the national labour market, expand academic knowledge and to work as a cultural bridge between Saudi Arabia and other countries by allowing Saudi students to understand and experience different cultures (Alqahtani, 2014). Since the programme started, an estimated 23,000 students are in American universities alone, and 20 percent of the cohort are women studying subjects like science, medicine and technology (Riedy, 2013). Such exposure to different societies may have a far reaching impact on the future of the country, with a new generation of Saudi students bringing back their skills and knowledge to help transform the country socially and economically (Alqahtani, 2014). Additionally, education increases women’s awareness of their rights, as noted earlier in the chapter, and as Moghadam states:

Access to education seems to have an immediate, tremendous impact on women’s perception of themselves, their reproductive and sex roles, and their social mobility expectations. (cited in Singh, 2013, p.226)

Another change in Saudi is related to the Islamic Religious Police ‘Committee for the Promotion of Virtue and the Prevention of Vice²⁹’ or as it is called in Arabic ‘Al-hai’a’ which was created in 1940 with the task of enforcing the Islamic law ‘Share’a’ and to preserve public morality (Doumato, 2000). They perform their tasks by, for instance, patrolling the streets, entering shopping malls, restaurants, and being present at other social gatherings to ensure that women wear their head scarves properly, that unrelated men and women do not mix, and that all shops close during prayer times. After having almost

²⁹ Also known as the ‘Committee for the Promotion of Commanding the Right and Forbidding the Wrong’.

unlimited power in the country, their responsibilities and rights have reduced over time. In 2002, when fifteen girls died in a fire because the religious police prevented firefighters from entering a primary school in Makkah on the grounds that the girls and women were uncovered, the government officially forbade the religious police from interfering in rescue work (Hamdan, 2005). However, although the authority of the Religious Police has reduced, they are still seen as a major obstacle to greater personal freedom since they influence people's everyday lives forcing citizens to conform to what they believe is Islamic public morality (Aart et al, 2012).

There have also been changes in the entertainment sector. During the 1930s, when the oil boom started as I noted earlier, western employers who came to the country at that time introduced the concept of film cinemas in Saudi Arabia. Since the cinema was a foreign concept, previously unheard of in Saudi, the first cinemas were found only inside the private residential compounds of the oil companies, and used strictly by their western employees. It was not until the 1970s when these became available to Saudi citizens and, at the same time, some cinemas opened in some Saudi sports clubs, and in some of the well-known family residences³⁰ in cities like Riyadh, Jeddah and Ta'if³¹. However, during that time, and driven by an overall Islamic movement called 'al-Sahwa al-Islamiyya'³² (Boukhars, 2006), which had its origin in the 1960s and was highlighted by the 'Grand Mosque Seizure'³³ in 1979, the government was pushed towards following a stricter path. As a result of the Grand Mosque seizure and the start of 'al-Sahwa', the Saudi government reacted by closing all the film cinemas in an attempt to contain the anger of the Saudi Islamic movement. Although this decision has remained in place until today, many Saudis managed to build a career in the film industry. For example, the Saudi Film Festival is organised by the Saudi Arabian Society for Culture and Arts (SASCA) and under the supervision of the Ministry of Social Affairs (Khan, 2017). This film festival started in 2014 and attracted many participants, men and women. Although Saudi Arabia is a land with no cinemas, the interest in the film industry is on the rise. Many Saudi youth are well-

³⁰ Wealthy people who lived in mansions constructed film theatres in their houses and invited friends and neighbours.

³¹ A city in the Western Province of Saudi Arabia at an elevation of 1,879 m on the slopes of the Sarawat Mountains.

³² Al-Sahwa al-Islamiyya' is a deeply conservative 'awakening' movement of the late 1970s and early 1980s that started when many Islamic scholars decided to start calling for what they believed was the real way of Islam (International crisis group, 2004).

³³ The seizure was led by Juhayman Al-Utaybi, who took control of the Muslim holy site in Makkah, and demanded adherence to a strict interpretation of Islam (Hegghammer & Lacroix, 2007).

known faces in Social Media and YouTube, where they found an alternative platform to convey and express their ideas and messages (Noman, 2016). The first Saudi film, 'Kaif Al-hal' was released in 2006, but was filmed in United Arab Emirates (Fattah, 2006). Nonetheless, in 2012, 'Wadjda' a film by the Saudi director Haifaa al-Mansour, was featured at the Venice film festival which is considered a first for Saudi Arabia in general and in particular for Saudi woman as Al-Mansour states:

Saudi Arabia is a very traditional, conservative and tribal society. Men and women cannot be on the streets together, particularly if the woman is seen to be directing the men. People would come and tell us to stop filming. It was a challenging experience, to say the least. (cited in Brooks, 2012, p.1)

Regardless of the challenges Saudi Arabia represents, many women such as Al-Mansour managed to leave their marks on society. With the recent changes within the country, more women are trying to overcome social barriers and play a role in the growth and the development of society. Further achievements of Saudi women will be discussed next in addition to Bahraini women's achievements.

Saudi and Bahraini Women's Achievements

More Saudi activists are now tackling issues of equality. One such woman is Suad Al-Shamary, the first Saudi woman lawyer who fights for women's legal rights in divorce, child custody and setting a minimum age for marriage, which still does not exist in Saudi (Singh, 2013). In the field of literature, many Saudi women have written remarkable books which have caused a lot of debate within society, and some have had to publish their work in other countries such as Egypt and Lebanon. Some of the most recognised and controversial names are Raja al-Sani, Qomasha al-Oliyan, Zeinab Hifni, Seba al-Harz and Warda Abdul Malik who discuss social issues such as marriage, oppression, abuse, sexuality, discrimination, and women's rights, subjects that are usually taboo or simply not discussed publicly (Aart et al, 2012). For example, in Warda Abdul Malik's novel, 'Al-wbia'a' (The Plague), she describes a religious character, a 'sheikh', who sodomises an illiterate woman while teaching her the Quran (Jaleel et al., 2016). The novel discusses ways in which many ordinary people think highly of religious scholars which gives them unlimited power. Even very conservative people who argue that 'ikhtilat' is forbidden, allow their women to stay alone with a religious scholar, or 'sheikh'. In Seba al-Harz's best-selling novel, 'al-Akharoon' ('The Others'), she writes about a lesbian community in

Saudi Arabia (Aart et al, 2012). Since homosexuality is strictly forbidden in Islam, it is considered to be a very difficult topic to discuss. For those novelists to write about and discuss such issues is a call to be more open about issues that I believe are important and should be addressed and discussed alongside issues related to disability. During the interviews, I talked with the mothers about the adolescence stage in which subjects such as puberty and sexual behaviour were discussed. These conversations caused discomfort for some of my participants, as I will explain in Chapter Five, to the extent that Huda for example wished that her son would never experience any sexual desires.

Another achievement for Saudi women is within the field of sport, which is usually only occupied by men. In 2012, and for the first time, two Saudi women, finally made it to the summer Olympics in London. The first female track runner Sarah Attar and Wojdan Shaherkani participated in the judo competition (Singh, 2013). In the Jeddah Chamber of Commerce, a group of businesswomen was formed to demand their rights in business industry. One of the well-known centres, ‘The Alsayedah Khadijah bint Khwailed Businesswomen’s Centre (AKBK)’, was established in 2004 as a part of the Chamber of Commerce in Jeddah (Alturki & Braswell, 2010). The centre is named after ‘Khadijah’ the wife of the Prophet Mohammad³⁴ who was one of the big names in the business and trading world in Islamic history, making her a role model and a source of inspiration for women nowadays. I contend that this very important Islamic figure has been marginalised by a male dominated society which controls the Chamber of Commerce with the purpose of limiting women’s roles in the Saudi entrepreneurial market. Such domination prevents women from forming business policies in the Kingdom, which in turn decreases an influential lobby emerging for women rights. Alsayedah³⁵ Khadijah met the Prophet when she hired him to be her business agent, and sent him her servant with a marriage proposal when she admired his morals and ethics (Elbayar, 2010). Choosing her name for the centre is obvious evidence of women’s role in society during the time of the Prophet. The Centre aims to emphasise the role of women in the business industry and to demonstrate ways in which they can become active members of social, economic and political development (Aart et al, 2012). ‘One of the main challenges facing businesswomen is the existing culture which might not accept women as leaders and decision makers’, writes Afnan Al-Zyani (in Singh, 2013, p.246). However, recently, the Centre was successfully able to

³⁴ Peace be upon him.

³⁵ Alsayedah is an honorific word in Arabia which is used when we mention the Prophets’ wives as a sign of respect.

change Article 114 of the Labour Regulatory Laws which stated that mixing of the sexes, 'ikhtilat', in the workplace is forbidden. It has now been replaced with a new law which states that men and women should follow the Islamic law 'Share'a' in workplaces without any mention of the word 'ikhtilat' (Aart et al, 2012). The Centre also succeeded in allowing women to invest in fields that were previously controlled by men, such as contracting, real estate and general services (Aart et al, 2012). Women are now allowed to be board members of private companies (Aart et al, 2012) and can start their own business without the need to hire the once mandatory male manager (Kelly, 2009).

By contrast, Bahraini women's achievements have been evident in the fields of media and journalism since the 1960s for example, when Alees Samaan joined the radio as the first woman and later became the Bahraini Ambassador to UK (Al-Obaidli, 2012). Further, 50 percent of workers in the public radio industry and 30 percent in television are women (Al-Gharaibeh, 2011). In addition, 50 percent of the editors of daily newspapers are women. In the legal sector, in 2009, ten women were members of the Bahraini State Council, three as judges in the criminal courts and one a judge in the constitutional court, unlike their Saudi peers who are not allowed to work as judges (Al-Gharaibeh, 2011). The empowerment of Bahraini women can also be seen in the police and military fields, in which women are not allowed such jobs in Saudi. Two women in the army have reached the rank of colonel with another woman reaching the same senior rank in the police force. Bahrain is the first Gulf country to allow women in high ranking professions and roles (Singh, 2013). By 1959, a small nursing school opened in Bahrain to offer training for women to work as nurses. After that, the College of Health Sciences was established in 1976 under the Ministry of Health, to educate men and women in the medical field (Singh, 2013).

As for political achievements, the Constitution in Bahrain, according to Article 1, ensures that all citizens have the right to be part of political affairs (Al-Obaidli, 2012). Therefore, women in Bahrain have the right to vote, to stand for public office and to participate in unions and there are many examples of Bahraini women in political positions (Al-Gharaibeh, 2011). In 1999, Sheikha Haya Al-Khalifa was Bahraini's ambassador to France, after which she became the President of the United Nation General Assembly in 2006, which makes her the first Arab Muslim women to chair a General Assembly of the UN (Singh, 2013). In 2002, Lula Al Awadi attained the rank of government minister when she was appointed as the General Secretary of the Higher Council of Women (Singh,

2013). The first woman ambassador to Washington DC, Huda Nonoo, was appointed in 2008, and in 2004, after serving in the Bahraini Parliament ‘Majlis Al-Nuwab’, Dr. Nada Haffadh was the first woman to be appointed as the Minister of Health in Bahrain serving in that position until 2007 (Singh, 2013). Also, Dr. Fatima Al-Balooshi was the Minister of Social Development, Shaikah May Al-Khalifa was the Minister of Culture and Sameera Rajab was the Minister of State for Information Affairs (Al-Obaidli, 2012). In 2002, Bahrain was the first Gulf country in which women had the right to full political participation, and was also the first country to have woman as members of the parliament ‘Majlis Al-Nuwab’ with 15 woman as members of the National Assembly in 2013 (Bahrain Factsheets, 2013). Bahraini women, including Dalal Al-Zayed, Nancy Khedouri and Jameela Salman, also took part in the Upper Chamber of Parliament³⁶ ‘The Al-Shura Council’.

To understand women’s achievements in both countries helps to understand the environment in which my participants lived, the challenges of encountering social norms and regulations, especially in Saudi Arabia. Although, as my data shows, mothers in both countries are faced with particular challenges with respect to autism and support, to have an enabling society that promotes women’s participation and encourages their accomplishments would allow them to feel good about themselves. From such positive feelings, they could believe in their capacity to provide care and support to their adolescents with autism. Bahraini women for example, participate in many and diverse areas of society, such as education, medicine, business and politics, and their active role has a positive impact on the society and their own lives (Al-Gharaibeh, 2011; Al-Obaidli, 2012, Bahrain Factsheets, 2013). Although, my participants in both countries are stressed and challenged by caring for children with autism, my data indicates that the Bahraini mothers have the capacity to better care for their adolescents. This may be as apparently simple as, in the case of Warda, the ability to drive around every day looking for an Autism Centre for her son, something a Saudi mother cannot do unless she has the financial capacity to hire a male driver or unless her spouse or another acceptable man will drive her. While I might argue for change, this must be contextualised.

³⁶ Consultative Council.

Resistance to Change

I discussed the changes in Saudi Arabia earlier in this chapter. However, despite attempts at liberalisation, the majority of citizens in Saudi tend to resist change (Fatany, 2007), blindly obeying traditions, and sustaining high levels of conservatism by refusing any change to the norm in which ‘many Saudi women see themselves as protected jewels’ (Al-Rasheed, 2013, p.23). As Doumato states:

Girls were taught enough to buy into an assigned role, a role in which they were subordinate to men, but not enough to challenge it.

(Doumato, 2000, p. 93)

I return to this example and to the issues it raises in Chapter Seven, with a detailed discussion of the Capability Approach and adaptive preferences. Many women do want to fight for change and to make a difference, not only to prompt a positive image of Saudi society, but also to work against what they regard as unfair customs and norms. This discord between conservative and liberal elements of society is noticeable in many ways. For example, women in Saudi Arabia were not allowed an identity card of their own, and had to appear on their male relative’s identity card, until 2001 (Rajkhan, 2014). Then the law changed and women were given their own identification cards with their faces unveiled. Predictably, perhaps, this change was met with resistance by both men and women, in, for instance, workplaces like banks in which an ID card is a requirement for processing transactions and other banking operations. Women who used their ID cards would be faced with obstructions thereby making any transactions a difficult process that demonstrated a form of resistance by the bank’s employees. Resistance to change also appears in the field of education. In girls’ schools many women teachers do not support theatre and literary activities and, until recently, physical education and sports activities were prohibited in girls’ schools. Likewise, when King Abdul-Allah ibn Abdul-Aziz opened the first mixed university in Saudi Arabia in 2009, ‘The King Abdul-Allah University of Science and Technology (KAUST)’ (Mcevers, 2009), many people did not welcome such a move. However, the university is still open and operational and it attracts many male and female students.

Other traditional practices are also enforced for some, such as insisting that women wear the veil, the ‘Burqa’. When I was volunteering as an interpreter in the oncology department of the ‘King Faisal Specialist Hospital and Research Centre (KFSHRC)’ in Riyadh, some mothers expressed their discomfort at my uncovered face. In their view, I was simply

breaking a sacred law. Comments like, ‘Why do not you cover your face?’ or ‘Your beautiful face should not be seen by men’ were quite common. While I was surprised that the mothers of children suffering from cancer were not occupied with more important issues than my uncovered face, I believe these reactions show how significant and deeply-held customs and traditions are in Saudi society.

Another powerful form of discrimination against and control of women in Saudi Arabia is transportation, which was a source of stress for many of the participants in my study. In a country in which women are not allowed to drive and in which no reliable or good public transport is available, they have to rely on their male relatives, fathers, brothers, husbands, or sons, for transportation. Women can hire male drivers and pay them a monthly salary to do basic chores like shopping, taking them to work, taking their children to school, and even going to hospital appointments but this assumes women can afford to pay a driver’s salary. In 1990, forty-seven courageous Saudi women drove their cars in Riyadh in protest at having no right to drive (Mtango, 2004). The government reacted by preventing the women and their husbands from travelling outside Saudi Arabia for a whole year, and the women who had government jobs were fired. King Fahad ibn Abdul-Aziz at that time officially forbade women from driving though this never became law (Al-Sharif, 2012). Wajeha Al-Huwaider and Fawzia Al-Ayouni, Saudi activists, formed the ‘Association for the Protection and Defence of Women’s Rights in Saudi Arabia’ and started a campaign called ‘The League of Demands of Women’s Rights to Drive Cars’. This group collected signatures and sent them to King Abdul-Allah ibn Abdul-Aziz asking for their rights to drive in 2007 (Singh, 2013) but they received no response.

Another example of resistance to the status quo can be seen in the activities of Manal Al-Sharif, a Saudi activist, who used to work as an internet security consultant in ‘Saudi ARAMCO (The Saudi Oil Company)’ and who started ‘the Saudi Women to Drive’ campaign’ in 2011 (Chaudhry, 2014). Manal released a video of herself driving on social networks, encouraging women who have international drivers’ licences to go out and drive on one day, June 17, 2011 (Chaudhry, 2014). Al-Sharif’s video was watched 600 000 times over two days and, as a consequence, 100 women came out on that day and drove their cars with some of them posting videos on social media of themselves driving (Chaudhry, 2014). Al-Sharif was arrested and put in jail, then released nine days later. She was also severely attacked by society, largely by other women, and she states the following.

They called me a whore, an outcast, licentious, immoral, rebellious, disobedient, and westernised, a traitor and double agent to boot. Pages sprang up on Facebook to denounce me, claiming that men would take their 'igals' (cords Arab men wear on their heads) and thrash any woman who dared break the taboo and drive. (Al-Sharif, 2012, p.59)

Although I believe the global focus is mostly on women's driving issues in Saudi Arabia, those issues go far more deeply than simply driving a car. As Al-Sharif said, 'It is about being in the driver's seat of our destiny' (Al-Sharif, 2012, p.6). It is about having the ability to make one's own decisions, about women being given choices, and about stopping the subordination because of their sex.

Many people in Saudi Arabia argue that women driving is a minor issue when compared to other problems the country is facing. Although, it might seem relatively unimportant, I argue, following my interview data, that this is an issue of a major significance. Such a ban is a symbol of society's belief that women are inferior, that they do not have the ability to take care of themselves and that they always need to be monitored as if they were children. Also, prohibiting women from driving increases their dependency on men and denies them their freedom of movement. In Nora's case this played a major role in her life and the life of her son, since one of the reasons Ahmad stayed at home until he was 10 years' old, was transportation. Both of Nora's brothers live at a distance from her and, lacking her husband's support, as I explain in Chapter Six, it was nearly impossible for Nora to take Ahmad to school. She also lives in a remote area which makes it hard to obtain transportation and she does not have the funds to hire a driver. She said:

Finally I found a disability centre Ahmad can attend but I had no-one to drive me. I asked my husband for help but he told me to handle it on my own. I asked everybody around, trying to find a driver. Then I heard about our neighbour, who drives the women of the neighbourhood for money. I contacted him and he agreed to drive us. I used to pay him with Ahmad's benefits which I receive from the government. His father will not even give me the money to pay the driver. The government only gives me S.R 600³⁷. I pay the driver S. R. 500, and the S. R. 100 left I use to buy other things for Ahmad. (Nora, SA)

Such issues are not faced by Bahraini mothers since they are allowed to drive. However, as in Saudi, if on a lesser scale, there is also tension between conservative and liberal

³⁷ £127.67

attitudes. While conservatives are content to accept the lack of gender parity, the liberals encourage the idea of partnership between men and women, and call for social justice. However, in a country like Bahrain where women have come a long way and played a major role in developing the society, the opportunities to overcome such outdated traditions are relatively good in comparison to Saudi Arabia. Shaikah Sabeeka states that ‘Bahrain women would not rest until they had achieved true partnership in the country’s development’ (cited in Singh, 2013, p.128). Saudi Arabia and Bahrain are similar in many ways - socially, religiously, politically and geographically and though restrictions and regulations exist which curtail women’s freedom and rights in Bahrain, they have significantly more freedom than do women in Saudi Arabia (Singh, 2013). In the next section, I will summarise the main differences between Saudi and Bahrain.

Saudi Arabia and Bahrain, the Differences

Fakhro states ‘Bahrain society has always been more cosmopolitan, pluralistic and less tribal than the societies of the other Gulf States’ (cited in Singh, 2013, p.62). As I discussed earlier, Wahhabi interpretations of Islam and traditional customs explain the lack of gender parity in Saudi Arabia and I would support Fakhro’s view, adding that Bahrain is, specifically, very much more cosmopolitan, pluralistic and less tribal than society in Saudi. The Bahraini constitution, for example, states that women should be treated as equal citizens in terms of rights and duties (Singh, 2013). By contrast, and as noted, Saudi Arabia does not have a constitution, and women’s rights are not documented anywhere since the country relies on tradition and custom to judge what is appropriate for what women can do and be. If the Quran does not address a certain subject, then the clerics tend to err on the side of caution and make it ‘haram’ (forbidden). The driving ban for women is a good example. Judges and clerics, therefore, have significant discretionary power to interpret the law, usually favouring tribal customs. One of the obstacles to gender equality in Saudi Arabia, which does not exist in Bahrain, is, as alluded to already, transportation. Bahrain, like Saudi Arabia, lacks a good public transport system but it allows women to drive their own cars. This is an important freedom since it gives women mobility and access to public spheres and does not make them dependent on male drivers. Another noticeable difference is that Bahraini women have freedom of choice when it comes to what they wear since they are not obliged to wear clothes that fully cover their body or hair as their Saudi peers must.

The legal system is also different, perhaps because Bahrainis come from diverse cultures and religions. The Bahraini court has a dual system that includes both civil and Islamic ‘Share’a’ courts, while Saudi Arabia only enforces the Islamic ‘Share’a’ law in its court (Al-Rayes, 2012). Civil law comprises those rules that enacted by the government with regard to how people should interact with one another, and is a sub-set of common law (Kuek & Tay, 2013). ‘Share’a’ law is taken from both the holy book, ‘the Quran’, and the teaching of the Prophet Mohammad³⁸ ‘Sunna’ and this is applied to all aspects of life, social, political and criminal. As discussed earlier, the misinterpretation of ‘Share’a’ law by the conservative regime in Saudi Arabia can often, in my view, make it seems rigid and unfair for women. Elbayer states:

Quran, supported by hadith and Sunna, is considered to be the primary source of Islamic law, like any written document these materials are, and have been, subject to human interpretation. (Elbayer, 2010, p.1)

As noted, too, judges have the absolute power to apply the ‘Share’a’ law in the Saudi courts, according to their interpretation of Islam and without any justification given to the public. To overcome this issue in Bahrain, a group of women asked the King, in 2001, to establish a personal law to protect their rights and welfare. A special committee called the ‘Personal Law Committee’ was created to support their cause and the law was finally approved in 2009 (Singh, 2013). Yet, the situation in Saudi remains largely unchanged.

Another major difference between the two countries is that women in Bahrain are not subject to ‘Al-Mahrram’, the law of male guardianship whereby women in Saudi Arabia are judged to lack ‘capacity’ and so must have permission from their menfolk to be educated, travel, seek medical attention, or travel abroad, for example. The law in Bahrain changed in 2004 to allow women to apply for, or renew, their passports, without permission from men (fathers or husbands). The minimum age of marriage is also different. Saudi Arabia does not have a minimum age for marriage whereas, in 2007, the Bahraini Minister of Justice and Islamic Affairs set the minimum age for girls to be married at 15, and 18 for boys (UNICEF, 2011). Though 15 is still, I suggest, young to be married, such rules protect women’s rights, and enable them to lead a better life. A similarity between both countries, however, is inequitable family law. A Bahraini woman cannot confer citizenship on her non-Bahraini husband while a Bahraini man can ‘give’ his nationality to his non-Bahraini wife and children. However, a positive change occurred in

³⁸ Peace be upon him.

April 2004, when the parliament issued a new law that allows Bahraini woman to sponsor her non-Bahraini husband and her children (Al-Gharaibeh, 2011). There have been no changes to the citizenship law in Saudi.

As in Saudi Arabia, there is discrimination in the workplace in Bahrain with women often earning lower salaries than men for doing the same job (Al-Gharaibeh, 2011). Another important point refers to social organisations which offer services for women. One of the charitable organisations in Saudi that takes care of orphans, poor and sick people is the Um al-Hamam Charity Association. It also has a women's branch where many women are being educated and trained for the labour market and provided with programmes to learn English language and computer skills (Aart et al, 2012). However, Bahrain was the first of the Gulf countries to establish social organisations to protect women's rights. One such association is 'Bahraini Young', which was established in 1955 with the goal of supporting women's development, helping them understand and obtain their rights (Al-Gharaibeh, 2011). A more recent social organisation is 'Bahraini Women', which was established in 2002 to support the constitutional rights and status of women (Al-Gharaibeh, 2011). The 'Bahraini Women's Union', established in 2006, works to spread awareness of women's roles in civil society (Al-Gharaibeh, 2011). In 2001, the 'Supreme Council for Women (SCW)', led by Princess Sabeekah Al-Khalifa royal family, was established to ensure gender equality, raise awareness of women's rights and deal with their issues and problems (Karloak, 2012). The SCW aims to promote qualified women and their important achievements, empower their political and economic roles and offer workshops and lectures to train them for the workforce. In 2011, the SCW opened a help centre to support women, offering them consultation, legal advice, and needed support (Bahrain Factsheets, 2013). With all that explained above, issues of gender discrimination remain a major concern for any society, in which social justice ought to be considered and promoted. However, there has been progress within the Saudi society.

By 2015, Saudi women were allowed for the first time to stand and participate in municipal elections; the Saudi government has also taken steps to recruit Saudi female graduates in many sectors including the primary national petrochemical industries as engineers and geological researchers (Pearson, 2015). However, from my perspective, women in Saudi and, though to a lesser extent perhaps, in Bahrain, are not yet able to fully realise their rights or, in the language of Nussbaum's Capability Approach and as I explained in

Chapter One, they are not yet able to realise their entitlements to be ‘fully human’ beings (Nussbaum, 2000) and live a flourishing life.

To empower women is more than just a matter of equality: it can also help improve the economic and the development status of the country (The Global Gender Gap Report, 2013)³⁹. As Afary states:

Middle Eastern/ Muslims women reached new milestones in the 1990s by placing women’s human rights, women’s centres and feminist scholarship on the political agenda. (cited in Singh, 2013, p.61)

Surely, such unfair tribal traditions and customs which allow discrimination against women should be eliminated and the law of a male guardianship is ought to be reconsidered. Extremist conservatives argue that Saudi Arabia is a special country which has its special circumstances and own privacy, and that Saudi women should not be compared to women from other countries (Aart et al, 2012). Such people, in my view, manipulate religion to serve their agenda ignoring the fact that Islam is a moderate religion which protects women and gives them the right to be involved in all aspects of society. As Azizah Al-Hibri, a feminist Islamic scholar notes.

When modern circumstances are compared to the experience of Muslim women during the life of the Prophet, the contrast is shocking. Early Muslim women were actively involved in every aspect of the life of the nascent Muslim society. They included businesswomen, poets, jurists, religious leaders and even warriors. (Al-Hibri, 1997, p.5)

The ‘real’ message of Islam does not deprive women of their rights but rather supports them. However, Al Hibri’s (1997) assessment of the role of women in Saudi society seems to have been discounted to the detriment of their full and equal status as citizens of the country, as will become clear in this thesis.

2.3 To Sum Up and Move Forward

In Saudi, tribal traditions are so embedded within society that they are often, but mistakenly, considered to be Islamic rules. My arguments here are undoubtedly those of a modern Muslim feminist seeking human rights for all women. It is my view and so my

³⁹ <https://www.theguardian.com/world/2014/dec/25/women-charged-saudi-arabia-driving-ban-terror-court>

position in this study that the voice of women in Saudi Arabia should be heard and recognised and that they should be considered as capable citizens with equal rights to men with Islam no longer being used as an excuse to prevent women from taking part in and fully benefiting from society.

Islamic rules and norms have, as indicated in this chapter, a major effect on all aspects of both Bahrain and Saudi, and will help contextualise the accounts of the women in this study. For the growth of any society, the role of women in developing the nation has surely to be acknowledged. Both men and women should be allowed full participation within their community and given the opportunity to shape their own futures. Bahraini society, unlike Saudi Arabia to date, has succeeded in fighting back against the traditional 'extremist' regime, giving it the ability to move forward, and achieve remarkable changes such as creating the Supreme Council for Women to enhance their role in the society. However, and as Shikah Hind Al-Khalifa states, 'The real challenge to Bahraini women is to change the conservative thinking' (cited in Singh, 2013, p.245). Although more effort is needed to enhance women's rights in Saudi Arabia, many Saudi women have managed to break the boundaries and achieve success in various fields as I discussed in this chapter. However, with limited empowerment, unfair rules and regulations, mothers of adolescents with autism in my study frequently talk of negative experiences with autism and support, as I will explain in the coming chapters. As for general issues regarding Autism Spectrum Disorder (ASD), stress and social support, they will be addressed and discussed in the next chapter. However and before leaving this chapter, it is worth reflecting on how Saudi Arabia and Bahrain, and Islamic cultures more generally, view disability.

The Quran does not address disability in particular although there is a widespread belief that individuals with disabilities will be rewarded in the afterlife for their 'struggles'. As the Quran states: 'Those who patiently persevere will truly receive a reward without measure' (Az-Zummar 39:10 cited in E-Da`wah Committee, 2015). This means that providing care and support for everyone, including individuals with disabilities, is encouraged not least because, as stated in the teaching of the Prophet Mohammad⁴⁰: 'A Muslim is a brother to other Muslims. He should never oppress them nor should he facilitate their oppression' (vol. 9, 85.83, cited in Weber, 2012, p. 87).

Therefore, policies such as the inclusion of all students, including those with disabilities, in the general school system follows the anti-oppressive Islamic principle of inclusion with

⁴⁰ Peace be upon him.

Islam opposed to ‘prejudice against and exclusion of any group of people’ (Guvercin, 2008, p.1). According to the teaching of Islam, all individuals are equal and all should stand against the marginalisation and exclusion of those who are different on the bases of their disabilities (Brown, 2013). The Quran states:

O mankind, We created you from a single [pair] of a male and a female, and made you into nations and tribes, that you may know each other [not that you may despise each other]. Verily the most honoured of you in the sight of Allah is [he who is] the most righteous of you. And God has full knowledge and is well acquainted [with all things]. (49:13, cited in Guvercin, 2008).

However, although both Saudi Arabia and Bahrain are Islamic states drawing on the Islamic law which is against discrimination and following which an individual with a disability has the right to be part of all sectors of society, marginalisation and deprecation continue to impede the inclusion of those with autism as noted earlier and as illustrated in the data that follows in this thesis.

Attitudes of shame, blame and segregation are against the belief of Islam and, as Sheikha Hessa Al Thani, former UN Special Rapporteur on Disabilities, states:

It is important to note that such attitudes do not stem from Islamic religious beliefs and according to the Islamic scholar Sheikh Isse A. Musse, of the Islamic Council of Victoria, ‘Islam sees disability as morally neutral. It is seen neither as a blessing nor as a curse. Clearly, disability is therefore accepted as being an inevitable part of the human condition. It is simply a fact of life which has to be addressed appropriately by the society of the day’. (cited in Weber, 2012, p. 87)

In my data that follows, there are examples of my participants maintaining that view of inevitability but there are examples, too, of what I, and some of my participants, suggest show society addressing disability, here autism, inappropriately.

According to Saudi laws and regulations⁴¹, and as noted earlier, people with disability should be granted full access to all sectors of society, including health services to ensure their well-being so to rehabilitation centres and resources that enable them to live a ‘decent life’ (see Nussbaum, 2006). In the last few decades both Saudi and Bahrain have moved towards a more inclusive education system although many would suggest, and I would agree, that both countries are still a long way from an inclusive educational system. According to Cushing, Clark, Carter, & Kennedy (2005), inclusive education is vital for students with disabilities to improve their

⁴¹<http://www.moh.gov.sa/en/HealthAwareness/EducationalContent/Diseases/Otherdiseases/Pages/004.aspx>

social and behavioural skills and to support them to become part of their society.

Full-time special education classrooms, what in Saudi are often referred to as inclusive classrooms, in state Saudi schools started between 1990 and 2000 (Aldabas, 2015). These classes are not specialised in autism, and children with different disabilities, such as a range of intellectual disabilities, autism and Down syndrome, are put together in the same class. While some might suggest that this is inclusive within those classes, as shown in the data here, such classes are not well equipped for children with autism and many autistic children do not benefit as much as they might from attending these schools (see Chapter Six). Currently, and according to Aldabas (2015), approximately 746 state schools have special education classrooms, which provide services for students with mild to moderate intellectual disabilities, and mild to moderate autism, while those with any disability judged to be severe attend special schools. The situation in Saudi, and Bahrain, is not, yet, a mainstream environment but children in these special education classes may, for example, join all other school pupils at breaks and some classes, such as physical education. As my data will show, these special education classes in mainstream schools do not always meet the needs of the autistic boys and young men in this study. Importantly, too, there exists no provision in either special classrooms or special schools for autistic young people after the age of eighteen. Even in autism centres, too, the needs of autistic young people are often not catered for and, again, the mothers in my data talk of this as a problem.

With respect to life after eighteen, business owners are encouraged by the Saudi government to hire individuals with disabilities. A disability card is usually issued by the Ministry of Social Affairs⁴² and this states the severity of the disability and suitable jobs for the individual. In 2014 a programme called ‘Tawafuq’ was launched with the Human Resources Development Fund (HRDF)⁴³ to fund jobs for all individuals with disabilities, with the aims of:

... subsidising and empowering people with disabilities to work in the private sector through providing suitable and sustainable job opportunities, achieving equal opportunities for people with disabilities in all programmes. (Ministry of Labour⁴⁴)

⁴² <http://www.arabianbusiness.com/disabled-saudi-count-as-more-than-one-for-nitaqat-573732.html>

⁴³ <https://www.hrdf.org.sa/Program/293/Tawafuq?bc=268>

⁴⁴ <http://bit.ly/2g5KIrr>; HRDF_Tawafuq website: <http://bit.ly/2foESQt> ; Qaderoon: <http://www.qaderoon.sa/en> ; Mowaamah: <http://bit.ly/2f2jcdA>

With this programme's focus on inclusion, approximately 62,728 Saudis with disabilities have been employed by 31,790 companies with almost 17,400 of them receiving subsidies.

With respect to Bahrain, UNESCO regards this country as having '... excellent integrative policies. Here the rights of children with disabilities to education represent a distinct criterion of social development in this society, in keeping with equal opportunities' (Ashencaen Crabtree, 2010, cited in Weber, 2012, p. 92). All children are entitled to education as the Bahrain report to UNESCO states:

All children should be subject to similar learning-teaching methods regardless of their social and cultural background and the different abilities and skills they possess. Education opportunities should be provided for all even for those with special needs of whom the ones with certain potentials should be integrated with the normal students. (Kingdom of Bahrain, 2008, cited in Weber, 2012, p.92)

An inclusive education initiative in Bahrain started in 2005, with disabled students the shared responsibility of the Ministry of Education and the Ministry of Social Development. This governmental programme funds the training of special education teachers by sending them to the Arabian Gulf University (Weber, 2012) and, in 2008, the Ministry of Education guaranteed that all students with disabilities would be included in the national education system. Further, the High Committee for Disabled Affairs, headed by the Minister of Social Development⁴⁵, provides care and services to all individuals with disabilities. Some of their responsibilities include establishing a national strategy which ensures training, care and services such as providing suitable jobs, preparing guidelines related to care and offering support for those with disabilities and their families. Additionally, it is the role of this committee to increase awareness of disability and to encourage programmes and activities which promote the importance of inclusion via different types of media. In some respects, arguably enabled due to its comparatively small size, Bahrain is closer to inclusive education than Saudi. However, and as indicated later in my data, major challenges remain.

⁴⁵ <http://www.mlsd.gov.bh/en/disabled/high-committee-for-disabled-affairs>

Chapter Three: Autism and Social Support

To give the short version, I've learnt that every human being, with or without disabilities, needs to strive to do their best, and by striving for happiness you will arrive at happiness. For us, you see, having autism is normal - so we can't know for sure what your 'normal' is even like. But so long as we can learn to love ourselves, I'm not sure how much it matters whether we're normal or autistic.

Naoki Higashida⁴⁶, 2013, p.33

3.1 Introduction

In the epigraph above, Higashida's inner voice about his feelings and thoughts trying to connect to, and communicate with, the world suggests accepting others for who they are, no matter how different they are from what we perceive as 'normal'. In this chapter, I will give a general overview of Autism Spectrum Disorder (ASD), its definition, characteristics, and purported causes. I will also discuss the adolescent stage because I am focusing on mothers who have adolescents with autism. Further, I will discuss autism in relation to carer stress for the same reason, since I am interviewing mothers who, as my data indicates, are often faced with hardship, difficulties and stress. Then, I will address social support for autism and note ways in which support can and could reduce levels of stress. I will use my data throughout the chapter to further explain the points noted above.

3.2 Autism Spectrum Disorder (ASD)

Terminology

Language is a powerful tool for communicating meaning, and expressing thoughts and ideas. The impact of our words when we address or refer to people is undeniable and this, of course, applies to the terminology we use to refer to individuals with disabilities. With respect to ASD, many disagree on how people on the autism spectrum should be addressed, and the terms used by individuals with autism themselves, their families, and professionals vary. An online survey of 3470 UK members of an autism community, conducted by Kenny et al. (2015), revealed that while a variety of terms are used the term 'autism' and 'on the

⁴⁶ The book 'The reason I jump' is written by a 13 year old Japanese boy with autism, Naoki Higashida. Naoki provides an insight into his life in a question and an answer format and it was translated into English by David Mitchell.

autism spectrum’ were preferred by individuals, their family and friends. The term ‘autistic’ was endorsed by 61% of autistic adults but by only 38% of professionals, while person-first language, ‘person with autism’, was largely used by professionals (49%) but by only 28% of autistic adults (Kenny et al, 2015, p.446). To put the person before the disorder, person-first language, is thought by some to indicate respect yet many individuals with autism prefer to be called autistic because they feel that autism is intrinsic to who they are: ‘I am not a person with autism, I am an autistic person ... I am autistic because I accept and value myself the way I am’⁴⁷ (cited in Thibault, 2014, p. 57). Further, for some disability communities such as the blind and deaf, the use of person-first language ‘violates that positive pronouns should precede nouns’ (Kenny et al, 2016, p. 443). For example, we do not usually say ‘people who are beautiful’ or ‘people with intelligence’ (Kenny et al, 2016, p.443). Many in the autistic community also express similar reservations. Sinclair (2013), for example, an autism activist, objects to such language arguing that the person should not be separated from their autism. Instead, Sinclair (2013) defends disability-first or identity-first language such as ‘autistic person’.

I did not address the issues of terminology with my participants, and I did not talk to their sons on the spectrum to ask how they would prefer to be described. Perhaps because they had all experienced the negative impacts of ASD, and because of their struggles, they often referred to autism in medically deficit terms talking of problems and autism as a disorder. In Kenny et al’s survey (2016) cited above, there was little consensus among autistic adults themselves on whether autism was disabling or whether society creates or perpetuates disability. Many professionals, while preferring person-first language, nevertheless feel uncomfortable using terms like ‘disorder’ and ‘disability’ because of the negative connotations associated with those terms and the implication that autism is something for which a cure can be sought. Nevertheless, UK professionals do not want to discount the real difficulties autistic persons face and they acknowledge the importance of such a label for gaining access to services and support (Kenny et al, 2016). As autism is still not well understood or generally supported in either Saudi Arabia or Bahrain, and because the language used to describe autism is predominantly based on deficit language and the medical model, I will, for the purposes of this study, use the language that reflects those

⁴⁷ Participants in Thibault’s study.

views, namely adolescents with autism. Further, while I endorse disability or identity-first language, autistic people in this study will be mostly described as ‘individuals with autism’.

Definitions of Autism

The word autism was first used by an American psychiatrist, Dr. Leo Kanner, in 1943 when he described the cases of eleven children in a paper titled ‘Autistic Disturbance of Affective Contact’ (Brereton, 2008). Kanner’s children were described as not being able to relate to others, unable to communicate, and obsessed with routine. In 1944, Hans Asperger, an Austrian psychiatrist, published a paper that described cases similar to those of Kanner in 1943 (Cohen, 2015). He diagnosed children having ‘autistic psychopathy’ if, like children with autism, they had problems with social interaction but, unlike autistic children, did not experience language delays or have unusual interests (Fischbach, 2007).

In both Saudi and Bahrain, autism diagnoses usually rely on DSM- 5 and I describe this here. Diagnostic classifications of the autism disorder⁴⁸ are described in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorder (DSM- 5, 2013)⁴⁹ as follows:

1) Persistent deficits in social communication and social interaction across multiple contexts, as demonstrated by the following:

- Deficits in social-emotional reciprocity, abnormal social approaches, no ability to maintain normal back- and-forth conversation, no ability to initiate or respond to social interactions.
- Deficits in nonverbal communicative behaviours used for social interaction, abnormalities in eye contact and body language, or deficits in understanding and use of gestures, a total lack of facial expressions and nonverbal communications.
- Deficits in developing, maintaining and understanding relationships, difficulties in sharing imaginative play or in making friends, absence of interest in peers. (cited in Carpenter, 2013, p. 1)

2) Restricted, repetitive patterns of behaviours, interests, or activities, as demonstrated by at least two of the following:

⁴⁸ According to DSM5, autism is classified as a disorder.

⁴⁹ The fifth edition of Diagnostic and Statistical Manual of Mental Disorders (DSM), a book developed by the American Psychiatric Association, that classifies and establishes criteria for mental health disorders and conditions.

- Stereotyped or repetitive motor movements, use of objects, or speech such as lining up toys, flipping objects and echolalia.
- Insistence on sameness, inflexible adherence to routines, or ritualised patterns or verbal nonverbal behaviour such as extreme distress at small changes, difficulties with transitions, and greeting rituals.
- Highly restricted, fixated interests that are abnormal in intensity or focus such as strong attachment to or preoccupation with unusual objects.
- Hyper- or hyperactivity to sensory input or unusual interests in sensory aspects of the environment such as apparent indifference to pain, excessive smelling or touching of objects (cited in Carpenter, 2013, p. 2).

3) Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life) (cited in Carpenter, 2013, p.5).

4) Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning (cited in Carpenter, 2013, p.5).

5) Finally, these disturbances are not explained by intellectual disability (intellectual developmental disorders) or global developmental delay. Intellectual disability and Autism Spectrum Disorders frequently co-occur (Howlin, 2015), in which most children with autism have an intellectual disability as I will explain later in this chapter. In a study conducted by Kika (2014), in Albania, on 98 children with autism aged from 2- 8 years, the results showed that 21% had a mild intellectual disability, 54% had a moderate intellectual disability, and 12% had a severe intellectual disability.

As there are no medical tests to diagnose autism, specialists rely on behavioural characteristics to diagnose the condition, and I shall return to this in the next section. These behavioural characteristics are usually and initially determined by parents' observations of their child's development. Such assessment can be quite challenging since many individuals with autism lack the cognitive ability to share their needs and experiences due to their limited communication skills (Gabriels & Hill, 2007). In addition to parents' reports, clinicians apply standardised tests such as the Autism Diagnostic Interview-Revised test (ADI-R)⁵⁰, The Autism Diagnostics Observation Schedule-Generic (ADOS-

⁵⁰ Structured interviews with parents or carers who are familiar with the developmental history of the child, used to diagnose autism.

G)⁵¹ and Childhood Autism Rating Scale (CARS)⁵² to diagnose the disorder (Kulage et al., 2014). In my study, all of the mothers interviewed were the first to notice their sons' different behaviours which they attributed to a variety of causes, such as the Measles Mumps and Rubella vaccination or the 'evil eye', as I explain in Chapter Five.

I focus in this thesis only on the medical and the social models of disability because the mothers in my study most often talked in ways that reflected the medical model whereas the social model fits more comfortably with the Capability Approach. Of course, there is a range of alternative models used for autism studies such as theory of mind, the spectrum model and the international classification of functioning, disability and health and I shall, briefly, outline these below.

Theory of mind refers to 'the cognitive capacity to attribute mental states to self and others' (Goldman, 2012, p.2) in which others:

... have minds that are different from our own. More specifically, it is the understanding that others have thoughts, feelings and perspectives that differ from ours which allows us to understand and predict the behaviours of others based on what we think they might be thinking. (Rastall, 2016, p.1)

This theory could be used to explain social impairment in individuals with autism who often find it hard to impute their beliefs to others or to predict their behaviours (Baron-Cohen et al., 1985). It might then follow that individuals with autism face difficulties in understanding others' emotions, thoughts and attitudes and, in not understanding that other people think and feel differently, they may fail to predict their behaviours and thoughts in certain situations. Accordingly, individuals with autism may not be able to communicate and relate socially to others and this could make them appear uncaring (Rastall, 2016). However, there is no reason to assume that individuals with autism are uncaring. It could be that they simply struggle to understand and that might lead to certain social characteristics of autism such as unsuitable reactions to others' emotions or assuming that other people feel and think as they do, being unaware of the impact of their behaviours on others, or not showing an interest in others' experiences or feelings (Rastall, 2016).

⁵¹ An observation-based assessment of socio-communicative behaviours such as social interaction, communication and play, used to diagnose autism.

⁵² Assessment scale used to distinguish children with autism from children with cognitive disability, in addition to discriminate between mild, moderate and severe autism.

However, we probably fail to understand what individuals with autism do or do not understand themselves as evidenced by Higashida in his book ‘the reason I jump’ (Higashida, 2013).

Another model I could have used is the International Classification of Functioning, Disability and Health (ICF): ‘a classification of health and health-related domains’⁵³, in which a standard language is used to define and measure health and disability. Approved by the World Health Assembly in 2001 (Üstün, 2011), according to the World Health Organisation (WHO) the aims of the ICF (WHO 2001:5) are to:

- provide a scientific basis for understanding and studying health and health-related states, outcomes, determinants, and changes in health status and functioning;
- establish a common language for describing health and health-related states in order to improve communication between different users, such as health care workers, researchers, policy-makers and the public, including people with disabilities;
- permit comparison of data across countries, health care disciplines, services and time; and
- provide a systematic coding scheme for health information systems⁵⁴.

The ICF focuses on the functioning of individuals with disability, functioning of the body, functioning of the individuals and the limited experiences they may encounter, functioning of the individual as a member of society, and the environmental factors which could enable or disable individuals with disability (Üstün, 2011). The WHO note that the ICF takes into account social elements of disability rather than regarding disability as a medical or biological dysfunction (WHO, cited by Weber, 2012). However, I do not use the ICF in this thesis because it is not generally used in Saudi or Bahrain and none of my participants referred to it.

⁵³ <http://www.who.int/classifications/icf/en/>

⁵⁴ http://www.wcpt.org/sites/wcpt.org/files/files/GH-ICF_overview_FINAL_for_WHO.pdf

Finally, I might have referred to the ‘Spectrum Model’, a model that locates autism as a spectrum disorder and so allows for a broad variation in symptoms. However, Gerrard (2006) suggests that this model has serious limitations. Firstly, Gerrard (2006, p.6) notes: ‘One problem is that characteristics of people with autism spectrum disorders (ASD) also appear in people who don’t have an ASD diagnosis, and who wouldn’t qualify for one either’. Secondly, she suggests that there are a wide range of characteristics that may lead to a diagnosis of ASDs. For these reasons and, again because this is not a model generally used in either Bahrain or Saudi and it is not referred to by the mothers in my study, I did not use this model in my thesis.

I have noted that the mothers in my study often used terms from a medical model and so I shall now, briefly, contrast the medical model with the social model of disability although I have alluded to these models in my discussion above. The medical model regards disability as ‘a personal deficit in bodily functioning’ (Barry, 2012, p.3) in which a person is disabled and cannot function like ‘normal’ people. The medical model views disability as a problem caused by ‘a disease, an injury, or some other health condition [that] requires medical care in the form of treatment and rehabilitation’ (Mitra, 2006, p.237). The social model, on the other hand, regards disability as ‘a social construction, one that is synonymous with oppression or disadvantage imposed by society’ (Barry, 2012, p.3). Disability is not a trait of the individual; rather, it is created by the social environment and requires change (Mitra, 2006). Michael Oliver (1990), a principal theorist of the social medical model, states that:

[i]t is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. (Oliver, 1990 cited in Mitra, 2006, p.237)

The medical model, however, regards autism as a disorder, a deficit that needs to be treated and perhaps cured, a view that accords with this study’s mothers’ own beliefs on and experiences of autism. By contrast, the social model of disability, crucially states that social conditions and attitudes can be more disabling than the disability itself if there is a lack of, for example, appropriate services, resources, options and opportunities. In my study, Asma’a (Bahrain) for example, talks about how society disregards individuals with autism:

As the Ministry of Labour and Social Development pay attention to the needs of senior citizens, for example, they should also pay more attention to individuals with disabilities and provide them with a suitable work environment, especially as autism is on the

increase. They need to use this workforce and to help the coming generation with autism be financially independent. (Asma'a, B)

The social model of disability holds that society discriminates against individuals with disability. Oppression and discrimination are caused by institutional forms of exclusion and by cultural attitudes that are deeply within social practices (Terzi, 2004), and Asma'a's experience above – indeed, the stories of many mothers in this study - helps illustrate the extent to which this seems to be the case in Bahrain and Saudi.

While the social model is an important and influential counter theory to the pervasive medical model of disability, the model, arguably, does not go far enough in addressing questions of social justice because it does not offer a complete theory of inclusion based on the person's needs or 'non-strategic capacities' (Terzi, 2004, p.148). Instead, liberal philosophical (and partial) theories of social justice, such as the Capability Approach (Nussbaum, 2006), look at features of the person other than her/his ability to contribute to the material wealth of society (by being economically productive). Principally, these features are the equal moral worth and dignity of the person (Nussbaum, 2006).

Nussbaum (2009, p.350), in her Capability Approach, argues that people with cognitive disabilities should be treated as equal citizens. As Nussbaum (2009) states:

They must be provided with equal entitlements to medical care, housing, and other economic needs. Also, people with disabilities must have truly equal access to education, even when that is costly and involves considerable change in current methods of instruction. Even that, our society has begun to realise. Now we must take the most controversial step of all, giving people with cognitive disabilities political and civil rights on a basis of genuine equality. (Nussbaum, 2009, p.350)

Following Nussbaum, societies would create environments in which individuals with disabilities are enabled to lead a life as close as possible to the general public, or, in the language of the Capability Approach, all individuals would be enabled to do and to be. With respect to autism, this would be not only about removing societal barriers such as access to services and resources, but also about the limitations autism places on some

individuals and their carers, as my mothers' experiences amply demonstrate (see, in particular, Chapters Five and Six). The impairments of disability should not be ignored, and individuals' limitations ought surely to be acknowledged. A non-verbal person with autism will encounter challenges in accessing basic resources and goods such as education or obtaining employment. What we should, however, ask is about the extent to which the social arrangements of the society in which they live enable or disable their capacity to participate as full citizens. Arguably, and from my participants' experiences, both society and ASD characteristics should be noted and considered, in order to understand the challenges they face in societies which do not yet recognise them as citizens of equal moral worth and dignity. But before moving to such an approach, I will now explain the characteristics of ASD in greater detail.

Characteristics of Autism

Autism Spectrum Disorder (ASD) is generally understood as a complex neurological disorder in which impairments in social interaction, communication and repetitive stereotype behaviour are identified (Hussein et al., 2011). In addition to the features of autism noted above for diagnostic purposes, further characteristics are important and were often mentioned by the mothers in my study.

ASD is also more common among boys with a prevalence of four to five times greater than in girls (Seltzer et al., 2001; Baio, 2014). Individuals with autism may find it difficult to interpret social relationships, they often display poor eye contact and fail to imitate body movements such as waving and clapping (Brereton, 2008). While typical children learn imitation during infancy, children with autism find this challenging. Because imitation is closely connected to learning other skills, such as joint attention⁵⁵ and the ability to play with peers, it is important for social development (Lowry, 2015). Also, individuals with autism tend to have impairments in verbal and non-verbal communication, they may have difficulties in understanding gesture and facial expressions, and they may develop an unusual tone of voice when speaking (Brereton, 2008).

⁵⁵ Social-communicative skill in which two people (usually a young child and an adult) use gestures and gaze to share attention with respect to interesting objects or events (Jones et al., 2004).

People with autism often interpret language literally, and may find it difficult to understand figurative speech (Happe, 2009). For example, a phrase like a ‘frog in my throat’ could be understood by an individual with autism as an actual frog in one’s throat (Anderson, 2009). Another common abnormal use of speech is echolalia, the ‘repetition of language spoken by others’ (Brereton, 2008, p.6) or ‘inappropriate, irrelevant or even meaningless repetitions of another’s or one’s own previous utterances’ (Stribling et al., 2006, p.4), as Nada, one of my participants reported (see Chapter Five). Echolalia can happen immediately after hearing others speak or can be delayed. Kanner considered echolalia to be one of the main symptoms of autism, and defined it as:

... things which have no meaningful connection with the situation in which they are voiced. The utterances may be interpreted by hearers as ‘silly,’ ‘incoherent’ and ‘irrelevant’. (Kanner, 1946, p. 242)

Though echolalia used to be understood as meaningless behaviour its function has been acknowledged over time and repeating terms and phrases may indicate that an individual with autism is struggling to understand conversation especially if it contains unfamiliar vocabulary (Stribling et al., 2006). Echolalia may also be resorted to in order to gain more time to understand and take part in the conversation (Saad & Goldfeld, 2009). Echolalia could also reflect emotions such as stress, anger and anxiety (Prizant & Rydell, 1984). Many individuals with autism also have a limited understanding of conversation which might occur because of a lack of social knowledge and a limited ability to use words in order to express their needs and demands (Brereton, 2008), as in Fatima’s case for example, when her son used to take her hand and walk her to the fridge when he felt hungry.

Further, people with autism often have unusual ways of playing with toys and can have an apparently inexplicable attachment to some objects (Memari et al., 2015). For example, instead of playing with toys such as cars and dolls in the way a non-autistic child might, autistic children tend to line up their toys according to matching colours and shapes (Memari et al., 2015). Nada, one of my participants described her son’s play:

I noticed other things like Adel’s way of playing; for example, he would line up his cars instead of playing with them, and he would also bang his other toys into the floor. (Nada, SA)

Autistic individuals also tend to follow rigid routines and can become very disturbed when their routine is interrupted (Brereton, 2008). For example, a person with autism may have a tantrum if taken on an unfamiliar route to school, if the furniture is changed, or even if s/he wears new clothes (Brereton, 2008). Rasha, one of the mothers in my study, talks about her son's need for routine:

Sami goes into one of his tantrums when his routine changes. He used to sleep in the living room since he refused to share a room with his brothers. When I finally managed to get him his own room, it was really hard for him to move there. He had a mattress he used to sleep on in the living room, and I moved it to his room. He would wait until I was not there and would take the mattress back to the living room and sleep there. (Rasha, SA)

Repetitive behaviour and rigid routines used to be thought of as a dysfunctional behaviour (Turner, 1999). However, it is now understood that when a person with autism feels uncertain about a social situation, s/he tends to seek reassurance by following a known routine. As routines offer structure and work as a coping strategy for unexplained social situations, they might also promote positive feelings such as comfort, calmness and happiness (Lopez et al., 2005). People with autism may also experience sleeping disorders, mood swings, self-injury and abnormal sensory nervous system issues (Brereton, 2008), in which, for example, sensitivity to certain fabrics can be heightened. This could explain why they might wear summer clothes in the winter, and winter clothes in the summer. Sensitivity to noise may be explained by an inability to filter voices and sounds, which is why they tend to cover their ears most of the time. David Mitchell, a novelist and father of a son with autism, eloquently describes the effect of this sensitivity:

A mind of a person with autism is a room where twenty radios, all turned to different stations, and blaring out voices and music. The radios have no off-switches or volume control, the room they are in has no door or window, and relief will come only when they are too exhausted to stay awake. (cited in Higashida, 2007, p. 2)

Individuals with autism may often feel aloof, distant and uncomfortable in their surrounding environment (Schriber et al., 2014). They often do not comprehend social situations so they struggle to make sense of what is happening. This occurs because Autism Spectrum Disorder seems to affect the function of the brain, resulting in poor social functioning that acts as an

impediment to the developmental of social relationships (Sparks et al., 2002). According to the American Psychiatric Association (APA) the social deficit in Autism Spectrum Disorder is:

Marked by impairment in the use of nonverbal behaviours, failure to develop peer relationships, a lack of seeking to share enjoyment, interests, or achievements with others, and a general lack of social or emotional reciprocity. (Lin et al., 2011, p. 144)

Crying, screaming and even self-injury are all forms of communication with which people with autism try to respond to social situations regardless of whether that response is deemed by others to be appropriate or not. Adam Harris, in his speech in TEDx⁵⁶, describes people with autism as people who have landed on an alien planet that was not built for them and in which they are unable to even speak its language. Higashida, the 13-year old autistic boy cited in the epigraph to this chapter, explains the isolation, loneliness and confusion that people with autism often experience:

For a long time I've been wondering why us people with autism cannot talk properly. I can never say what I really want to. Instead, verbal junk that hasn't got anything to do with anything comes pouring out of my mouth. This used to get me down badly, and I couldn't help envying all those people who speak without even trying. Our feelings are the same as everyone else's, but we cannot find a way to express them. (Higashida, 2007, p. 39)

To identify such characteristics early is critical, since early intervention programmes could be of benefit to enhance the child's social and communication skills, as I will explain in the next section and refer to again in Chapter Five in which I outline mothers' reactions to and feelings about autism pre and post diagnosis.

Early Diagnosis and Intelligence

The ideal age for diagnosis is about 18 months old but early signs can be noticed when the child is as young as 6 – 12 months (Brereton, 2008). Early signs in infants and toddlers may include the following: lack of spontaneous smiling, no eye contact with their mothers during breastfeeding, lack of imitation of facial expressions and movement, and a very quiet or very upset baby for no obvious reason (Smith et al., 2013). Also, the baby may not

⁵⁶ An international event where motivational speakers present their ideas (<https://www.ted.com/participate/organize-a-local-tedx-event/before-you-start/what-is-a-tedx-event>)

lift her/ his arm to be picked up and may not show attachment to her/his mother or their primary caretakers (Brereton, 2008). Further, it is well known that behavioural characteristics of autism vary between individuals: some children show developmental delays from birth while others enter a phase of regression after a certain age⁵⁷ and period of normal development (Sicile-Kira, 2004). Nouf, a Bahraini mother, shares her experience with her son's regression:

Sultan was a normal child. I remember him calling his nanny's name when he got hungry. He was aware of his surroundings, and had the ability to comprehend and communicate. When he was about nine months old, he would wait for his father at the door to arrive from work. He would also count the stairs with me as we went up or down. He would hold his father's car key in his hand and say 'baba' as a sign of wanting to go out. All of that disappeared when Sultan reached one year old. (Nouf, B)

As for the severity of autism, when the disorder is accompanied with severe intellectual disability it is described as 'low functioning autism' (Howlin, 2015), a description that many autistic people eschew (Kenny et al, 2016). Additionally, the level of intellectual disability can have a direct effect on behavioural problems. Individuals with autism who have severe intellectual disability tend to have more behavioural problems than those who do not have intellectual disability and known as 'high functioning autism' (Woodman et al., 2014). The connection between autism and intellectual disability is explained by Vivanti et al. (2013), as follows. The child's brain is shaped by the social experience they acquire at an early age, therefore, the severe characteristics of ASD deprive the child from such experiences which are essential for their intellectual development. However, this area might not be studied as rigorously as desirable as standard IQ tests require certain skills such as quick verbal response and good motor skills (Sicile-Kira, 2011). Because these skills are often difficult for individuals with autism, these IQ tests might not be entirely accurate in determining their level of cognitive ability (Sicile-Kira, 2011). For example, two of my participants received a misdiagnosis of intellectual disability as explained in Chapter Five.

Many of my participants wondered why their sons had autism. For example, Huda, a Saudi mother, blamed herself thinking it was something she had done during pregnancy that had

⁵⁷ Not specific, some mothers in my study reported a year, others reported regression at a younger age.

affected her son's health. What Huda may not have realised is that the causes of autism, if there are any, are not well understood and I next discuss what is known so far about the causes of autism.

Causes of Autism

The causes of autism are unknown. However, it is thought that genetics combined with environmental factors could be involved (Sicile-Kira, 2004). If a child is born with autism, it is estimated that having another child in the same family on the autistic spectrum could vary between five and six percent and, in the case of identical twins, it is estimated that there is a 60% chance that both twins will be born with autism (Orozco, 2014). Currently, no specific genes have been identified as causing autism and there are no medical genetics tests available to screen for autism (Sicile-Kira, 2004). Further, environmental factors such as mercury toxicity, air pollution, pesticides, mothers smoking during pregnancy and the father's age are believed by some to play a role in causing ASD. The MMR vaccine (a vaccine against measles, mumps, and rubella), viral infections such as cytomegalovirus⁵⁸ and the herpes encephalitis⁵⁹ virus, have also been implicated in causing autism but there has been no conclusive research linking these conditions to the disorder (Cohen, 2008; National Health Services, 2012). However, a study by Al-zaalah et al. (2015), on 277 Saudi families of children with autism showed that 43.6% of them believed that MMR caused their children's autism. In my study, two of the Bahraini mothers had the same belief (see Chapter Five). Another study conducted by Alqahtani (2012), with 47 Saudi parents of children with autism showed that the MMR vaccine was the most common reason believed by families to cause their sons' autism, followed by cultural causes such as the evil eye and black magic.

Lenny Schafer⁶⁰, a publisher of the largest UK daily publication on the cause of autism, states that the:

The autism epidemic is like an epidemic of out-of-control hit-and-run accidents. Something big and dangerous collides with your child and leaves him or her devastated from the assault. We don't know the

⁵⁸ A herpes virus which may cause severe damage to the neurological system and is transmitted through body fluid such as urine and saliva and could pass through sex, kissing, or blood transfusion.

⁵⁹ A viral infection which could directly infect the brain or cause the immune system to attack healthy cells in the brain,

⁶⁰ <https://leftbrainrightbrain.co.uk/2005/02/03/autism-misinformation-and-lenny-schafer/>

offending vehicle nor the driver nor the time of the collision. But these cars don't wreak the same damage on everyone they hit. It seems some more than others, and most not at all. (cited in Sicile-Kira, 2004, p.38)

The above quote represents many of my participants' feelings about their sons' autism. Among the difficult questions I encountered during the interview were: 'What is the reason for autism? Why did it happen to my son? Is there a cure?'. These were questions to which I did not have the answer. As in the quote above, I did not know the 'offending vehicle nor the driver'.

Although until recently autism was thought to be a rare condition, many more children are now recorded as affected by the disorder. In Glasgow, Scotland, for example, in 2014 1,565 pupils, between the ages of 5 and 19, were recorded with a diagnosis of autism⁶¹. Information about the affected children usually comes from surveys, collected data, and published research and studies (Public Health Institute, 2001, p.16). Even though the precise reasons for the rise in the numbers of those diagnosed with autism are as yet unknown, because knowledge and understanding of autism is expanding, better and earlier diagnoses can be made resulting in higher numbers of diagnoses (Sicile-Kira, 2004). It may be, however, that the disorder is increasing among the population (Mugno et al., 2007). In 2000, the USA Centre for Disease Control and Prevention (CDCP) established the autism and disability monitoring department to collect data that would provide estimates of the prevalence of the Autism Spectrum Disorder and other developmental disabilities in the USA (Sicile-Kira, 2004). In 2007, the estimate was that one child in 110 had autism, whereas the latest statistics indicate that one child in 68 is diagnosed with autism which reflects a 78% increase (Sicile-Kira, 2011). In 2012, about one child in 68 or 1.5% of children were identified with ASD across the United States⁶². In the UK, the National Autistic Society (NAS) stated that in 1993, 91 children out of 10,000 had autism compared with 35 children out of 10,000 in 1979. In 2001 the estimate had increased to one child in 166 (Sicile-Kira, 2004). Autism appears to be common as 700,000 people are on the autism spectrum in the UK a figure that means more than one in 100 people are on the spectrum⁶³. Overall, and according to the World Health Organisation, 15% (4.2 billion people) of the

⁶¹ file:///C:/Users/Wid%20Daghustani/Downloads/Data%207%205%2015.pdf

⁶² <https://www.cdc.gov/ncbddd/autism/data.html>

⁶³ <http://www.autism.org.uk/about/what-is/myths-facts-stats.aspx>

world population lives with a certain type of disability, with 2 to 4% experiencing functioning difficulties (Al-Jadid, 2013). As for the Global Burden of Disease, 15.3% of the world population have moderate or severe disabilities, while 2.9% have a severe disability (Al-Jadid, 2013). The WHO⁶⁴ estimate that worldwide one in 160 children have what they term an ASD, ‘... a range of conditions characterised by some degree of impaired social behaviour, communication and language, and a narrow range of interests and activities that are both unique to the individual and carried out repetitively’. The WHO Autism Spectrum Disorders Fact sheet (updated April 2017) also notes that, from epidemiological studies conducted over the last fifty-year period, ‘the prevalence of ASD appears to be increasing globally’. That increase, notes the WHO, might have a number of explanations ‘including improved awareness, expansion of diagnostic criteria, better diagnostic tools and improved reporting’. The World Atlas website⁶⁵ states that national research studies have indicated ‘that Japan and other developed countries have the highest rates of autism’ but it may be that the language is ambiguous here. On the WHO view that possible explanations for increased statistics of those with autism include increased awareness, improved diagnostic criteria, tools and reporting, it may be more accurate to suggest that Japan and other developed countries have the highest reported rates of autism. As my data, mainly in Chapter Five, indicates, the diagnosis of autism remains an issue in both Saudi and Bahrain (and, of course, in many additional countries of the world).

Of course, children with autism grow to be adolescents with autism. The increase in the number of children diagnosed with autism obviously means that there are many more adolescents with ASD, which not only potentially increases demands for services, but also suggests the need for more research in this area and I will discuss the adolescent stage in the next section.

Adolescents with Autism

Adolescence is a transitional stage from childhood to adulthood, beginning at the time of puberty, around 11 to 14 years, and continuing until the early twenties (Brereton, 2011). Many changes accompany this process including cognitive, physical, psychological and emotional changes, as well as, for some, difficulties in establishing social identity

⁶⁴ <http://www.who.int/mediacentre/factsheets/autism-spectrum-disorders/en/>

⁶⁵ <http://www.worldatlas.com/articles/countries-with-the-highest-rates-of-autism.html>

(Brereton, 2011). Also, the adolescence stage may bring with it issues such as aggression, anxiety, mood swings and obsessive behaviours (Brereton, 2011). During the adolescence stage, individuals tend to pay increasing attention to others' feelings and thoughts. Relationships outside the family grow and relations with peers become hugely important. However, adolescents with autism tend to miss out on the social interactions with their peers which can have a major effect on their ability to learn social rules and regulations (Strunk, 2011). With limited understanding of norms and regulations, and difficulties in understanding people's feelings, it may be challenging to make friends. For example, an adolescent with autism might stop a stranger in the street and try to shake her or his hand just because she/ he learned that this is the way to greet people (Brereton, 2011).

Contrary to some misconceptions, people with autism do show interest in people. Higashida explains that individuals with autism are full of feelings and eager to make friends.

Whenever I overhear someone remark how much I prefer being on my own, it makes me feel desperately lonely. It's as if they're deliberately giving me the cold-shoulder treatment. (Higashida, 2013, p.21)

Autism as a developmental disorder will continue to affect how individuals relate and communicate with others. As children with autism grow, their social and communication issues can become more difficult to manage. Behaviours such as tantrums in public places, making odd noises, and aggression towards self and others, may be relatively easy to deal with in children but are rather more difficult when it comes to adolescents with autism (Gabriels & Hill, 2007). Also, it is estimated that 30% of individuals with autism develop seizures when they reach adolescence (Seltzer et al., 2001). Fong et al. (1993) in the USA, identified six parental concerns during the adolescence stage that were social concerns such as inappropriate social behaviour; behavioural concerns such as aggression and tantrums; family concerns such as restrictions on families' activities; education concerns such as available specialised schools and provided services; relationships with professionals such as lack of communication and mixed messages and, finally, future concerns such as the independence of the child (Seltzer et al., 2001). My participants experienced few of these concerns as I will explain in Chapter Five when I discuss the adolescence stage. Rasha for example, reported that Sami's behaviour became aggressive when he reached the adolescence stage:

Sami used to be a very peaceful child. He used to be nice to everyone. Now he is aggressive all the time. He actually hits children on purpose. We are always alert, and we never allow a child to walk in our home without supervision. My daughter has a young child, and my other daughter has a twin. When they visit us, we put all the children in a room and close the door. We are scared because when Sami sees them, he beats them really hard. (Rasha, SA)

Other sources of stress for parents of adolescents with autism are a lack of independence, lack of access to services which are mostly available for children, safety issues, sleeping disorders and the environment in which they live which might or might not be altered to meet their needs (Seltzer et al., 2001), all issues that the mothers in his study reported. Noha, for example, shares her experience with Khalid for whom there is no place to play now that he is an adolescent:

When Khalid was younger, I used to take him to shopping centres where he could play in the games. They do not allow him to play now because of his size. I explain to the person in charge that he has autism, and they ask whether is harmful, whether he hurts others or hits them. I say 'No' to them. 'My son is safe just please allow him to play'. Sometimes they agree, but most of the times they do not. (Noha, SA)

A number of further studies indicate changes in autism symptoms in relation to the age of individuals. Although adolescence can be difficult to manage, the severity of autism may decrease as the child grows, especially with so-called high functioning autism. Depending on the parents' ability to deal with the disorder, and the child's cognitive ability, managing autism may be less stressful when children reach their teens (Seltzer et al., 2001). Venter et al. (1992) found an IQ increase in 58 high functioning adolescents with autism at the age of 13 - 14 year old in England, when compared to their childhood. In a study conducted by McGovern & Sigman (2005) among 48 adults with autism in the USA, symptoms were reported to be less severe in young adults compared to children. In addition, Esbensen et al. (2009) who conducted a study on 700 children and adults with autism in the USA, found less frequent and less severe repetitive behaviours among adults when compared to younger children with autism. Other studies, however, show a worsening in the characteristics of autism during adolescence and adulthood (Fecteau et al., 2003; Woodman et al., 2014). Gillberg & Steffenberg (1987), in their study of 23 people aged 16 - 23 years old in Sweden, reported that 35% experienced periods of aggressive behaviour,

22% continued to deteriorate throughout puberty with a loss of language and cognitive abilities.

Another concern of particular relevance to my study is the availability of services needed by adolescents with autism, such as suitable schools and job opportunities. For example, Mai's son had to stay at home because there were no available public schools for boys with autism above the age of 12, as I will explain in Chapter Six. Autism, as a lifelong developmental disability affects not only individuals with autism, but also their families. Based on the literature and my participants' views, it is not easy to be a parent of a child with autism and many parents suffer a great deal of stress, especially in societies in which women's freedom is severely restricted (see Chapters Five, Six and Seven), and so I now turn to issues of stress amongst the carers of children and young people with autism.

Autism and Stress

Raising a child on the autistic spectrum can have a strong impact on the lives of parents and carers who may experience many challenges such as anger tantrums, self-injury and language impairment (Seltzer et al., 2001). An invisible condition with no cure can put the family under enormous stress with ongoing behavioural issues, continuous needs, and little or lack of independence of the child. Living in societies, such as Saudi Arabia and Bahrain with little or no awareness of the spectrum, may also lead to the isolation of the family, as Nouf, a Bahraini mother of a 16 year old boy with autism explains:

People lack awareness of autism. For example, during this last Eid Alfitr⁶⁶ celebration I took Sultan out with us to buy him new clothes. I wanted him to feel part of the family and to feel what it is like to celebrate. We were at the shopping centre. I was in one of the stores paying for the clothes and Sultan and his father were standing next to me. Sultan started moving in a different way, the usual autism moves - everyone stopped working to stare at him. However, his father and I didn't care about others - we continued with what we were doing and left the store. (Nouf, B)

Nouf and her husband experience high levels of stress, mostly because of the little support they have as I explain in Chapter Six. Such high levels of stress can result in decreased parenting self-efficacy and increased family distress (Boyd, 2002; Cantu, 2010; Karst, 2013). As noted earlier, such stress could be related to various factors such as the

⁶⁶ A religious holiday celebrated by Muslims worldwide at the end of the month of Ramadan.

permanency and the severity of autism, associated developmental issues such as delayed speech, the dependency of the child, lack of social acceptance, difficult behaviours such as repetitive behaviours and questions, and inadequate social support (Sharpley et al., 1997; Bornstein, 2006; Plant, 2011). Further, parents of individuals with autism report negative impact on the family, distant parent-child relationships, high levels of depression and poor well-being (Montes & Halterman, 2006; Alan & Lauren, 2008; Cox, 2014). Research has clearly demonstrated that parents, particularly the mothers of children with developmental disabilities are more likely to exhibit higher levels of parenting stress and mental health problems than parents of children without disabilities (Koegel & Lazebnik, 2009; Cantu, 2010). Parents of individuals with autism report higher stress in comparison to parents of children with other developmental disorders such as Down Syndrome⁶⁷, fragile X syndrome⁶⁸, cerebral palsy⁶⁹, and undifferentiated developmental disability (Sanders & Morgan, 1997; Seltzer et al., 2001; Mancil et al., 2009). Dumas et al. (1991) compared parents' level of stress, depression, and child behavioural problems in parents of autistic and Down Syndrome children with behavioural disorders and children with typical development in the USA. They studied 150 families, 30 with autism, 30 with Down syndrome, 30 behavioural disorders and 60 with typical development. The study showed that parents of children with autism and children with behavioural disorders reported higher levels of stress and greater depression than the parents of children with other disabilities or more typical development. In another study conducted by Sanders & Morgan (1997), 45 families of children with autism, Down Syndrome and no disabilities were interviewed in the USA. Mothers of children with autism reported higher levels of stress, more family problems and difficulties in finding help such as a babysitter because of the characteristics of the disorder such as self-injury, sleeping disorder and aggression. In addition, Hutton & Caron (2005) found that mothers of children who have autism experience high levels of emotional stress, anxiety, fear, and guilt. Elder & D'Alessandro (2009) pointed out that families of children with autism are often faced with immense challenges, and familial and marital stress is typically high. In my study, all my

⁶⁷ 'Down syndrome is a genetic disorder caused by the possession of a third copy of chromosome 21. The disorder causes lifelong intellectual disability and developmental delays, and in some people causes health problems' (Carr et al., 2007, p.56).

⁶⁸ 'Fragile X Syndrome (FXS) is the second most common genetic cause for intellectual disability. It is caused by expansion in the number of repeats of the trinucleotide CGG in the so-called FMR1 gene on the X chromosome. It results in a wide range of developmental, physical and behavioural problems' (Carr et al., 2007, p.497).

⁶⁹ 'Cerebral palsy is the most common disorder of motor development, movement and posture. It results from an insult to, or anomaly of, the immature central nervous system in centres which govern motor activity' (Carr et al., 2007, p.500).

participants experienced feelings of stress during their journeys with autism, for many reasons such as issues with diagnosis, lack of adequate support, and lack of suitable education, as I will discuss in Chapters Five and Six.

Although parents may struggle to acknowledge that their child has a disability, their relationship with their child could have an impact on her/his ongoing development (Caspi et al., 2004). Positive parent-child relationships can help the child cope, not only with the disability, but also with overcoming difficulties in order to learn and progress (Woodman et al., 2014). Smith et al. (2008) examined the relationships of 149 adolescents and adults with autism and their mothers in the USA. The results showed that the warmth and praise of the mothers had a significant impact on the behaviour of the adolescents with autism: the better the relationship, the less were the behavioural problems. Because, as noted above, parents of individuals with autism often experience a significant amount of stress, social support is needed, especially since support is positively linked to reducing parental stress levels (Weiss et al., 2013).

Social Support

As I discussed above, the autism disorder varies from one individual to another in terms of severity, social skills, intellectual disability, behavioural problems, and so on. Those differences in behaviour and needs affect families differently and each individual requires what is suitable for him or her in terms of services and support (Sicile-Kira, 2004; Sicile-Kira, 2006; Wall, 2007; Cox, 2014). Social support can be either formal or informal, and may involve psychological, physical, or financial support (Boyd, 2002). Formal support, as understood and used in this thesis, is provided by professionals, organisations, individualised education programmes (IEP) team members, healthcare providers, counsellors, therapists, respite care personnel, and schools (Boyd, 2002). Informal support would come through parental networking and include support provided by family members, parent support groups, friends, and neighbours (Renty & Roeyers, 2006; Mendoza, 2007).

Boyd's (2002) research on the literature of effects of social support in general on mothers' levels of stress, showed that mothers of children with autism gain social support from formal or informal sources. Where there is little social support the mothers' level of stress

may increase resulting in their withdrawal from social activities that may, in turn, affect their emotional well-being. Rasha shares her story with her 13-year old boy with autism: *People wonder why I do not have a social life, why do not I visit my cousins and my neighbours. When they come and visit me, and see Sami's condition, they are shocked. They do not expect him to be that bad. And of course I cannot take him anywhere with me; and I cannot leave him behind either. Even if I think of leaving him at home, who is going to take care of him? No one knows how to handle Sami or to how to deal with him. (Rasha, SA)*

Although parents of individuals with autism report high levels of stress, they can, with the appropriate support, deal with autism. Since seeking social support in times of stress is a natural response, parents who do get appropriate support seem better able to understand the disorder, face its challenges, and learn to function well (Elder & D'Alessandro, 2009). Mothers seek social support for many reasons such as the child's behavioural problems, her/his cognitive limitations, stress and depression (Boyd, 2002). In a study conducted by Gray & Holden (1992), 172 parents of children with autism in Australia answered a questionnaire on coping and social support. The data revealed that parents who obtain social support report less stress, depression and anxiety. Also, as discussed in White & Hasting's (2004) study in the UK of 33 parents of adolescents with intellectual disabilities who sought to improve their sources of support reported improved well-being and reduced stress and anxiety levels. In Kerns & Siklos' (2006) study in British Columbia, parents of 56 children with autism and parents of 32 children with Down syndrome, both aged 2-18 years' old, received support from the same source but it differs in quality with parents of children with autism receiving less support. Additionally, the parents of children with autism showed significantly less satisfaction with the provided support and they believed that adequate support would help increase family adaptation and coping strategies. Bristol et al. (1993), in a study of 28 mothers of children with autism in the USA, found that formal support given by professionals had a positive effect on reducing maternal depression. Similarly, in a study of 60 mothers of individuals with autism aged from 2 to 18 in the USA, Gill & Harris (1991) found that mothers who received social support reported less stress in comparison to mothers who did not. Herman & Thompson's (1995) study on informal social support showed that mothers had lower stress levels and lower depression rates because they received good support. Additionally, in a study conducted in 1999, Bailey et al. addressed the social support needed by 200 parents (50 Mexican, 50

Puerto Rican) living in the USA, of children with developmental disabilities. Results showed that parents needed to gain more knowledge about the disorder, to have more information on the child's situation and how to cope with it, and to better understand how to find support services. Results also showed that formal support from official organisations and informal support coming from family members was more helpful than informal support from friends and neighbours. However, the mothers of children with autism appear to gain more benefit from informal sources of support such as parents groups, family and friends with respect to their level of stress (Boyd, 2002). Further, Hadadian (1994) studied 15 families who had children with developmental delays in Kuwait and found that mothers who received informal support from their spouses had better relationships with their children, and that the support of family, friends, and the surrounding community played a major role in reducing mothers' stress level. During the interviews with my participants, most of them indicated that they lacked social support as I will demonstrate in Chapter Six, and many seemed to be very stressed.

It seems reasonable to suggest that appropriate services and trained professionals should help to meet parents' needs and requirements. Providing opportunities to acknowledge and express their positive and negative feelings, the ability to express anger, fear and sadness, can also help parents cope with autism. Social support should also surely provide information about the disorder, as well as resources, available services, organisations, and specialised centres. The literature demonstrates the importance of both formal and informal social support in reducing mother's stress level and suggests that informal support, especially from the spouse, can have a significantly positive effect on mothers' well-being (Ekas et al., 2010). For example, this is the view of one of the mothers in my study, Asma'a, the Bahraini mother of 20-year-old Khan:

The most important support anyone can find is within the family. I think the family makes a difference to whether the mother can handle and deal with her son's disability or not. I am grateful I have a supportive family who helped me through this. This is life anyway, people are different, and not everyone is the same. We have to accept those who are different from us! (Asma'a, B)

Just like Asma'a, the rest of my participants were affected by the available social support or the lack of it. They expressed emotions of loneliness and anxiety, feeling that only they could offer support to their autistic sons. Preece (2008) stated that the overwhelming majority of studies have shown that the autism disorder can have a significant negative

impact upon the family and its functioning. In places where available and accessible support services are provided, parental stress levels seem to decrease. Parent support groups are seen to be beneficial in helping mothers to share their feelings and discuss their child's situation freely without the fear of being judged or criticised (Krauss et al., 1993), something I hope this study might accomplish by making it available to other mothers who live in similar situations. By reading it, they would know that others share their experience and that they are not alone and I return to this in the final chapter.

Additionally, Tunali & Power (2002), in a study of fifty-eight mothers of children with autism in the USA, showed that in order to cope with the stress of having a child with autism, parents placed more emphasis on family than career, and greater emphasis on receiving and providing social support than those parents without children with autism. As noted, a lack of social support can cause high levels of stress. Bitsika & Sharpley (2004) study demonstrated that lack of social support was seen as one of the most stressful factors when raising a child with autism. The same study showed that a mother's stress level could rise and fall in inverse relationship to her perceived levels of social support. In order for parents of adolescents with autism to develop and use effective coping strategies, they often depend on family support networks for assistance, as well as on formal support. Moreover, mothers who have access to informal and formal support reported lower levels of depression and anxiety than those who did not. Such conclusions emphasise the positive impact of social support on mothers of adolescents with autism and the adolescents themselves. Noor shares her story about formal support for her 12-year old son, Waleed:

The Autism Centre told me about a private teacher who teaches children with autism at her place, and who sometimes does home visits. I called her to start teaching Waleed. She had no availability but she managed to fit my son into her schedule. She was terrific. All the basics Waleed knows are because of her. She used to come to my place three times a week for two hours, and sometimes longer. She even used to take Waleed with me out to shopping centres to allow him to mix and socialise with others. (Noor, B)

3.3 Autism: Saudi Arabia and Bahrain

As explained earlier in the chapter, autism is a neurological disorder that affects all social classes, ethnics groups and cultural levels (Rutter, 2005). An online study by Alnemary et al. (2016), of 250 parents of children with autism in Saudi Arabia on the services available

for their children showed that the age of acquiring services is 3 years' old. 94% of the children received non-medical treatment, 88% biomedical treatment, and 84% received culture and religious treatment. Culture is defined, as noted earlier, as the characteristic ways in which people of certain groups perceive and interact with their environment. Moreover, culture is the external expression of people's mental life in the form of language, beliefs, customs, technology, human relationship, and many other factors (Hussein et al., 2011, p.5). People's reactions toward the autism disorder vary from one culture to another, and cultural norms may determine, at least influence, one's thoughts and behaviours. In a religious country like Saudi Arabia or Bahrain, a disability is often understood to be a punishment from God for previous sins, especially concerning autism when no clear reason for the disorder can be given to parents. Such attitudes create feelings of shame and guilt that play a major role in seeking help and support from others (Gautam & Jain, 2010; Hussein et al., 2011).

With specific regard to autism, although mothers have more freedom in Bahrain than in Saudi Arabia and it is easier to take care of their adolescents in Bahrain, as my data will demonstrate, Bahraini society is still judgmental. Asma'a, a Bahraini mother says:

My main problem was with the people around us. Whenever we go out with Khan, people stare at us; it doesn't seem like they understand what autism is. For example, I remember one time when we were travelling to Kuwait and Khan was making noises on the plane. One of the passengers started making comments about him which really hurt me. When we go out to restaurants, people start looking and making comments. People act as if Khan is some strange creature with weird behaviour which attracts attention anywhere we go.

(Asma'a, B)

As I explained in Chapter Two, and will discuss further in later chapters, Saudi Arabia is a deeply conservative and religious country, governed by both the strict interpretation of Islam (Wahhabism). Tribal/customary laws and restrictions on women's movement and unequal social status and gender discrimination are pervasive. Hence, the mothers of adolescents with autism are women living with significant cultural restrictions. They tend to be the primary caregivers who have to face the challenges of taking care of an adolescent with autism while they are deeply affected by the customs and traditions of the country. Bahrain, on the other hand, has a more progressive approach to equality of the sexes and this has led, as explained in Chapter Two, to remarkable changes for women in

that country. However, having little to no guidance provided for parents of adolescents with autism is a source of worry and frustration among many mothers, from both Saudi and Bahrain, in this study.

Children on the spectrum grow up, and with them often grow their issues and their needs, and so they require different forms of services and support with access to support sometimes not as easily available as it was for their sons at a younger age. Warda, a Bahraini mother of a 14-year old boy with autism, shares her experience and her frustration at the lack of support she received from her son's centre:

I told the guy responsible for the Autism Centre, "You proved that you can only handle babies and young children, but you cannot deal with older boys. My son is only a sample and there are a lot of harder cases out there". I started telling him the names of our Bahraini kids who are in Jordan, and I said to him, "You want us to bring our teenagers back from Jordan? With the way you are handling things it wouldn't be possible". (Warda, B)

As well as social expectations, the behaviour of a child who was once socially acceptable can be perceived completely differently once the child matures:

A small child with big eyes gets his head patted by the strangers who pass his way, even if he ignores them. But a five foot nine, fifteen year old boy with acne and an inability to make eye contact isn't going to be greeted as warmly. (Koegel & Lazebnik, 2009, p.4)

3.4 To Sum Up and Move Forward

In this chapter, I have outlined the Autism Spectrum Disorder, and introduced issues particular to the adolescent stage, social support and stress on mothers. Mothers who are the primary caretakers also struggle with providing lifelong care in an environment that, in Saudi Arabia especially, has very particular rules and regulations. In Chapter Five and Six, I will use thematic analysis to address autism and social support. Since restrictions on women make care even harder, I will use the Capability Approach in Chapter Seven to address the issues of women in both Saudi Arabia and Bahrain, and to explore ways in which a just society, according to Nussbaum, should take into consideration the ten central

human capabilities when evaluating the well-being of its citizens. In the next Chapter, I will discuss the research methodology I used to frame the data collection and analysis.

Chapter Four: Research Methodology

Research is to see what everybody else has seen, and to think what nobody else has thought.

Albert Szent-Györgyi⁷⁰

4.1 Introduction

Research may often be to look differently at what others perceive as typical, and, as the epigraph above suggests it may be to see things differently. To deeply understand mothers' position in a conservative society, and to challenge what others believe are inevitable and immutable norms and regulation, is an attempt to contribute, even if only in a small way, towards a 'new' understanding of social justice and the lives of mothers caring for children with autism. In this chapter, I will present the methodology and research design used to explore the realities of mothers of adolescents with autism in Saudi Arabia and Bahrain and, specifically, their lives and stories with respect to autism, support, society and cultural norms. I will explain how I contacted the mothers to arrange the interviews, and the difficulties and challenges I faced in doing so. I will also describe the procedures used in translating and transcribing the recorded interview conversations, in addition to explaining how the themes and sub-themes emerged from the literature, from the research tools and from the data itself. Additionally, I outline, in section 4.5 the ethical considerations that were necessary and relevant to this research.

As Kvale (2006) explains, interviews can be a sensitive and a powerful method by which to explore participants' experiences and I decided they would allow me to explore the behaviours, emotions and perspective of the mothers whose stories I wanted to consider. Although I had a set of themes and sub-themes that I wanted to discuss, I did not present mothers with a list of pre-designed questions. Rather, I engaged in conversations in order to hear and understand the stories of their lived experiences – their stories. I will explain in detail the themes and sub-themes I planned to cover during the interviews. After translating and transcribing extracts from the interviews, and on further examination of the extracts, other sub-themes emerged. My decisions on the themes were influenced by the literature review and, as noted, by Nussbaum's ten central capabilities (discussed in Chapter Seven). The capabilities are used to help analyse the data and make sense of the mothers' stories

⁷⁰ <http://quoteinvestigator.com/2015/07/04/seen/>

about the hurdles and obstacles they face in dealing with autism in what I contend is an unjust society that means I ask about the extent to which they can sustain the capabilities so fundamental to a flourishing life.

4.2 Research Objectives

As discussed in Chapter One, the aim of this study is to expand the research knowledge regarding the journeys of mothers of adolescents with autism. My objective was to understand the journey, as mothers experience it and to better understand their lived experiences caring for their sons with autism. Further, the mothers' problems with social support, both formal and informal, and descriptions about what they consider to be support, the individuals providing it and if anyone understands their situation were all important elements of this research. Bitiska & Sharpley (2004) indicate in their study of parents of children with autism that they may struggle with the belief that therapists and professionals may not have the ability to understand their children or attend to their needs, and this was the case with most of my participants. Many of the mothers I interviewed had little confidence that professionals had the ability, or willingness, to provide adequate support for their adolescents. Further, the mothers showed significant concern with regard to the provision of support (which the literature describes as formal and informal and outlined in Chapter Three). Formal support includes professionals such as doctors, therapists, nurses, or behaviourists who usually have a certification in a field of expertise (House et al., 1988; Gill & Harris, 1991; Sharpley et al., 1997). Informal support includes a spouse, immediate and extended family members, friends, or neighbours and can include advice, suggestions, and information to address problems (House et al., 1981; Konstantareas, 1991; Bitiska & Sharpley, 2004; White & Hastings, 2004). Furthermore, the study aimed to investigate mothers' experiences in two related but different societies – Saudi Arabia and Bahrain, and to consider ways in which the cultural norms and laws might have an impact on the lives and the well-being of the mothers caring for their adolescent sons with autism and so I will now outline the research design, starting with the approach taken.

4.3 Research Design

Qualitative Research and the Interpretive Approach

Interpretivism aims to explain the subjective reasons and meanings that lie behind social action (Thomas, 2010, p.296) where information is usually influenced by its cultural

surroundings. In this study, the reasons and meanings lying behind the mothers' actions can be interpreted as stemming from a lack of social support, sex segregation, and among other things, stigma associated with disabilities of any kind in traditional societies. To understand the person's inner struggle, and see the situation through her eyes, the interpretive method allowed me to position myself epistemologically to 'understand and interpret through meaning of phenomena (obtained from the co-construction of knowledge/reconstruction of meaning of lived experience)' (Denzin & Lincoln, 2013, p.216). Thus, I did not assume I knew what mothers were thinking or that I understood how their stories had unfolded and the focus of my research was to learn from the mothers I interviewed. This approach, further, allows the researcher to understand and investigate the data in its 'social and cultural context where the event occurs' (Thomas, 2010, p.301) as I did in both Saudi Arabia and Bahrain, and in the mothers' own settings. In such research, each experience is unique and may even change from day to day. This means that the situation may be flexible and fluid. In my study, one mother's experience may be similar to another's, but her experience will differ depending on the support of her husband, her family, her access to transport, and the services available to support her child with autism, for example. Also, by using this approach, and accepting that each experience is unique, I was able to demonstrate that understanding the mothers' situations is complex, rather than simple and easy.

As Habermas, (1974) argues, we ought to 'clarify, understand and interpret the communications of "speaking and acting subjects"' in order 'to understand social facts in their cultural significance and as socially determined' (cited in Cohen et al., 2001, p.32). Further, to interpret the data is to 'make meaning of that information by drawing inferences or by judging the match between the information and some abstract pattern' (Thomas, 2010, p.296). Lederman & Abell state that:

Interpretive researchers carefully document the context (physical, social, cultural) that shapes and, in turn, is shaped by participants' interactions, thereby generating practical knowledge of the complexity, context, and dynamics of teaching and learning.
(Lederman & Abell, 2014, p.42)

Though understanding the information I obtained from the mothers during the interviews is crucial, such understanding not only depends on the information I gathered, but also on my interpretation of such knowledge. To reach such understandings, I explored mothers' lived

experiences in order to establish the connections and patterns between their struggles with autism, the cultural aspects and the social context in which all their stories occur.

For this study, I decided that a qualitative approach, using interviews as the method of data collection (see below), would be the most useful for following an interpretive approach and for facilitating an open dialogue with participants, the mothers of adolescents with autism. Such an approach allows the participants degrees of freedom when answering questions (Moustakas, 1994). Anderson & Arsenault define qualitative research as:

A form of inquiry that explores phenomena in their natural settings and uses multi-methods to interpret, understand, explain and bring meaning to them. (Anderson & Arsenault, 2002, p.119)

Lincoln & Denzin (1998), also define qualitative research as involving ‘the studied use and collection of a variety of empirical materials’. These can include, they explain, case studies, personal experience, introspection, life stories, and interviews, for example, and that describe ‘routine and problematic moments and meanings in individuals’ lives’ (Denzin and Lincoln, cited in Anderson & Arsenault, 2002, p.120).

Further, according to Myers (2009), qualitative research is designed to help researchers understand people, and the social and cultural contexts within which they live. Beardworth & Keil (1992, cited in Bryman, 2012, p.495) explain that qualitative research frequently entails the reconstruction of events by asking interviewees to think back over how a certain series of events unfolded in relation to a current situation, as my mothers did when I asked, for example, about their affective responses to the diagnoses of autism. This method allows for open-ended questions, interviews, observation data, and document data, and gives participants the freedom to tell their own personal experiences while allowing the researcher to collect rich and complex data that can be developed into themes (Liamputtong, 2007). In my study, I wanted the participants to have the freedom to tell their personal stories using their own words so that I could collect rich data to try and understand their experiences and the issues the mothers face in both societies.

Moreover, according to Liamputtong (2007), qualitative research may be the most suitable method for studies related to vulnerable people. Considering the position of women in Saudi Arabia in particular, these are mothers of adolescents with autism in a conservative

society, and this can make them vulnerable to loneliness, isolation, anxiety, depression, and so on, as I explain in Chapters Five and Six. This is because, as Gregory & McKie (1996, cited in Liamputtong, 2007, p. 8) explain, ‘the nature of the qualitative research allows the researched to express their feelings and experiences in their own words’ which the mothers in my study did freely. The aim of the study, as I discussed above, was to understand directly the lived experiences of mothers of adolescents with autism, and following the interpretive approach, to talk with them in their natural settings (their country), to make sense of, and interpret, phenomena in terms of the meaning these mothers bring to them (Guba & Lincoln, 1998), and to be ‘introspective’, if they wished about their life stories, specifically, their struggles with the autism disorder, support and society from their own points of view. By using this, I was able to form a relationship with the participants creating bonds of trust that allowed them to share their stories with me, and to ‘describe routine and problematic moments and meaning’ (Guba & Lincoln, 1998, p.2). According to Merriam:

The researcher engages the situation most often without an observation schedule, and plays a dynamic role in constructing an understanding of the research environment through self-interpretation of what happens... thus, qualitative research produces a result which is ‘an interpretation by the researcher of others’ views filtered through his or her own’. (Merriam, 1998, p.23)

Interpretive studies, then seek to explore peoples’ experiences and their views or perspectives of these experiences. They are studies that are, typically, associated with qualitative approaches to data gathering and analysis (Gray, 2014, p. 37), such as interviews, the research instrument adopted for this study and outlined below after a section in which I consider ways of ensuring that my study can be deemed ‘good research’.

Good Research?

I come from an academic background and tradition that remains at least hesitant, and often suspicious of, qualitative research. I was aware that selecting an interpretive approach and using qualitative data from a relatively small number of interviews would be open to criticism especially from those still determined that a positivist approach quantitative approach was the only way of doing ‘good research’. To try to ensure that my research was ‘trustworthy’, I used Guba’s (1981) four constructs, his trustworthiness criteria, for

qualitative research. Following Shenton's (2004, p.64) discussion of Guba's criteria these are:

- 1) credibility (in preference to internal validity)
- 2) transferability (in preference to external validity/generalisability)
- 3) dependability (in preference to reliability)
- 4) confirmability (in preference to objectivity).

With respect to credibility, I have used many verbatim extracts from my participants and so hope to provide a 'true' account of what they said during the interviews. But I do not say this is 'the truth' because I understand that my data is a 'snapshot' of only some of their experiences and that if I interviewed them today then they might tell me about different experiences and different feelings. With respect to transferability, I try in this chapter, and the earlier chapters, to provide enough detail of the methods and the context of my study, in both Bahrain and Saudi but I never claim that the study is generalisable or even that my participants are representative. With respect to dependability I have tried to be clear about my methods and ways of working but I do not think another researcher would want to 'repeat' my study. Another researcher might, however, be able to learn something from it with respect to a similar study and so I try, in this chapter especially, to be clear about what I did at all stages of my research. With regard to confirmability, I sought to give voice to my participants by not putting 'words in their heads', by trying not to 'lead' them in my interviews, and by working very hard to listen to and read the data so that their voices and thoughts, not my voice and thoughts, or those of other authors, were reproduced here. My voice is here but when I use it I try to make it clear that I am doing so and that I am not speaking for my participants.

Interviews as a Research Tool

As I discussed above, because of the interpretive methodology of this research study, interviews were an appropriate method for data collection. Kvale describes the interview as:

An attempt to understand the world from the subjects' points of view and to unfold the meaning of their lived world'. Interviews, further, give voice to common people, allowing them to freely present their life situations in their own words, and open for a close personal

interaction between the researchers and their subjects. (Kvale, 2006, p. 481)

Interviews are often used to collect personal information about beliefs, values, lived experiences and cultural knowledge (Liamputtong, 2007). In this study, interviews were chosen as the method of data collection because they would allow me to collect such information if mothers were willing to share it with me while remaining sensitive to the gender gap that exists between men and women, especially in Saudi Arabia, and which might make women vulnerable and subject to discrimination.

Interviews can be semi-structured, open-ended and highly structured with fixed questions. I used semi-structured interviews because they tend to be more flexible and responsive to the direction of the interviewee, and can provide rich detailed answers (Bryman, 2012).

Beardsworth & Keil (1992, cited in Bryman, 2012, p.472) stated that ‘as the interviews progress, interviewees themselves can raise additional or complementary issues, and those form an integral part of the study’s findings. In other words, Beardsworth & Keil (1992) suggest, the interview schedule does not need to be based upon a set of relatively rigid pre-determined questions and prompts. Rather, the open ended, discursive nature of the interviews ‘permit an iterative process of refinement, whereby lines of thought identified by earlier interviewees could be taken up and presented to later interviewees’ (Beardsworth & Keil, 1992, cited in Bryman, 2012, p.472). Open-ended interviews contrast with structured interviews in which standardisation may be important since it depends on the validity and reliability of the measurement, and where interviewees are supposed to answer a set of questions (Bryman, 2012). In interpretivist research, the questions tend to be open-ended to allow for, as I explained, the collection of rich data on the lived experiences of participants, here the mothers whose stories I was trying to collect and to understand.

Charmaz (2002) discusses three types of questions during an interview, which I used while talking to the mothers in this study: initial open-ended questions, intermediate questions, and ending questions (in Bryman, 2012, p. 479). By way of example, an initial open-ended question in this study is ‘Tell me about your journey with autism?’. An example of an intermediate question is ‘How did you feel when you first heard you son had autism?’, and of an ending question, ‘What do you think is the ideal situation for you and your son?’. As is typical of interpretive research, open-ended interviews can give freedom to both interviewer and interviewee to express their personal opinions using their own

vocabularies, while allowing access to complex knowledge (Cohen et al., 2001). In this study, complex knowledge included mothers' struggles with autism, understanding, sympathy, and various kinds of social support. Rana, for instance, shares her complex life experience, her determination not to run away from her troubles:

Unlike my husband who chose to run away and separate himself from us, I did completely the opposite. I stopped going out, stayed away from everyone including relatives and friends. I decided to dedicate myself completely to my boys. (Rana, SA)

Interviews can also help minority opinions to be heard, giving people voices to share their viewpoints with others. Because of the kinds of societies the mothers in this study come from, their voices are often treated as if they were a minority. Yet, they are crucial to this research; listening to what they have to say, their opinions, their struggles and how they see and describe their experiences enriches our knowledge of what it is to be a mother with particular kind of experiences, in a particular kind of society. Hence I turn now to the research questions asked in my interviews.

4.4 Research Questions

The phases, themes and sub-themes of the questions were as follows and as shown in Table 4.1 below.

The phases that helped to structure my interviews were:

1. **Phase One:** pre-diagnosis of autism including misdiagnosis, with the subthemes of mothers' awareness, their affective and behavioural responses such as confusion (affective) and seeking medical help (behavioural), and their interpretation of their sons' different behaviours. Misdiagnosis is included here when mothers received inaccurate diagnoses of their sons' conditions.
2. **Phase Two:** immediately following the diagnosis of autism, including time and place of diagnosis, who made the diagnosis and mothers' affective and behavioural responses to the diagnosis.
3. **Phase Three:** post diagnosis including manifestations of autism and the adolescence phase. Subthemes include mothers' awareness, mothers' affective responses, their interpretation of their sons' behaviours and mothers' behavioural responses.

I sought to ask questions about each of these three phases in my interviews although I did not follow a 'strict' researcher focussed order but, instead, listened to the mothers' stories in the order that they recounted them.

The types of support I sought information on were:

1. Informal social support, including spouse support, family and friends, neighbours, drivers and helpers.
2. Formal support, including hospitals, schools and Autism Centres, and other institutions providing support and services.
3. Societal support, including societal awareness, peoples reaction to autism, and mothers' opinions of society.

Additionally, and in each interview, I sought, but was often given without my questions, mothers' views on their stories with respect to cultural rules and regulations, including gender discrimination and laws.

To cover the study themes I mentioned above, the mothers engaged in a conversation that allowed them to speak freely while I tried, in our conversations, to answer the following key points:

1. When did the mothers notice their sons' different behaviours?
2. How did the mothers feel about these behaviours?
3. What were the mothers' reactions to these behaviours?
4. Where did the mothers go to seek help?
5. When and where did the mothers manage to obtain an autism diagnosis?
6. How did the mothers feel about their sons having autism?
7. What were the mothers' reactions toward autism?
8. How did the mothers handle the characteristics of autism?
9. What changes did the children experience with autism when they reached the adolescence stage?
10. How did the mothers handle these changes?
11. What support is available for mothers and their adolescents with autism?
12. How do mothers perceive the level and quality of support and how do supporters, if at all, fulfil their roles?
13. What type of support do mothers believe is more helpful: informal or formal?

14. What are the limitation mothers face in terms of cultural rules and regulation such as gender discrimination and sex segregation?
15. What do mothers think of the society they live in, and what is its attitude towards autism?
16. What would be the ideal situation for their sons?
17. What kind of future do mothers see for their sons?

Table 4.1 below summarises the phases, themes and sub-themes.

Table 4.1 Data Themes

THEME ONE – AUTISM				
PHASE ONE: PRE-DIAGNOSIS INCLUDING MISDIAGNOSIS				
Awareness	Affective Responses	Interpretation	Behavioural Responses	
PHASE TWO: IMMEDIATELY FOLLOWING THE DIAGNOSIS OF AUTISM				
Awareness	Affective Responses	Behavioural Responses		
PHASE THREE: POST DIAGNOSIS INCLUDING MANIFESTATIONS OF AUTISM AND ADOLESCENCE PHASE				
Manifestations of autism				
The Adolescent Phase				
Awareness	Affective Responses	Interpretations	Behavioural Responses	
THEME TWO - SOCIAL SUPPORT				
SOCIAL SUPPORT - INFORMAL				
Spouse				
Behaviour of the spouse (including positive and negative behaviour)	Mothers’ affective responses to spouse’s behaviour	Mothers’ behavioural responses to spouse support		
Family and friends				
Behaviour of family and friends (including positive and negative behaviour)	Mothers’ affective responses to family and friends	Mothers’ behavioural responses to family and friends’ support		
SOCIAL SUPPORT- FORMAL				
Hospitals	Positive	Negative		
Autism Centres and Schools	Positive	Negative		
Other institutions	Positive	Negative		
Society	Positive	Negative		

4.5 Ethical Considerations

Following Farrimond (2016, p.72), writing in the British Educational Research Association (BERA) Handbook of Educational Research, ‘Doing ethical research is a fundamentally important part of educational academic practice’. Although what she calls ‘behaving “well” ’ is not new, she suggests that an increasingly formal culture of ethical reviewing ‘has emerged which has put the ethics of education research in the spotlight’ (Farrimond, 2016, p.72). Reminding us that ethical thinking with respect to research is ‘... based on principles or values ... theorized to guide decision-making’, Farrimond lists a core set of principles (citing Kitchener and Kitchener, 2009; Shamoo and Resnick, 2009) as follows:

- 1 Respect for persons (autonomy, protection of the vulnerable)
- 2 Justice (treat people fairly)
- 3 Beneficence (do good)
- 4 Nonmaleficence (do no harm)
- 5 Fidelity (do not lie/fabricate, be trustworthy)
- 6 Academic freedom. (Farrimond, 2016, p.76).

In my research it was, of course, important to follow all of these principles and to do so both in order to conform to the University of Glasgow’s ethical approval process and in the light of particular ethical considerations which arose because of the topic, context and approach used in my study. The academic freedom principle was not especially relevant as my research was not being funded directly and there were no competing or potentially restricting interests apart from ensuring my research met the requirements of the other five principles. I explain how I did this below and, in this section, I also discuss reflexivity as an ethical consideration with respect to my own emotions and the emotions of the participants in the study.

Before conducting the study, I submitted a formal application for data collection to the Ethical Approval Committee which was approved July 10th, 2015. With the application, I explained the purpose of the research, the methodology, and details of the interviews. Translated consent forms which contained all the information about the researcher, title and purpose of the study in Arabic, were given to the mothers whom I met face-to-face. I also explained verbally the study in detail and their right to withdraw from the research at any time, along with the assurance of confidentiality and anonymity. I offered the same explanation to the mothers I interviewed via the ‘phone and obtained verbal consent from them. In all cases, I made sure the mothers fully understood the research information, which allowed them to make voluntary decisions on whether to take part in the research and continue to participate. All the participants I interviewed were adults and competent to

agree to the study. With respect to the above, I therefore sought to make my research conform to the principles of respect for persons, justice and fidelity.

All mothers and their adolescents with autism were given fictitious names, and I assured them that every effort would be taken to anonymise and protect their own and their sons' identity. Real names are not mentioned in any part of the research. I also explained that they would not be identified in any way by the research findings. These factors and the removal, for example, of the towns/cities in details of my participants, all contribute to respecting them as persons and protecting them from any possible identification.

Additionally, I removed details of jobs from any data reported here if those jobs could identify the participants. All the raw data, the transcripts and translated texts were kept safe in locked drawers and the computer files password protected. According to the 5th principle of Data Protection Act 1998 (The National Archive, 2005) all data was to be destroyed upon the completion of the study.

Of course, and as I noted at the start of this section, ethical issues are important, especially when working with what might be called 'sensitive' research. As Miller & Bell (2002) emphasise, ethical considerations need to be followed throughout the research process: where they should take part before, during and after the research. Furthermore, my participants revealed intimate and personal details about their lives and about the people around them, so as a researcher, I had to ensure the well-being of my participants. I had to make sure they would not be negatively affected by participating in my research, so striving to ensure my research met the nonmaleficence principle. Researchers, as Melrose states:

Have a duty to ensure that no harm comes to their subjects, whatever their ages, as a result of their agreement to participate in research. If we cannot guarantee that such participation may improve their lives, we must ensure, at least, that our scrutiny of them does not leave them worse off. (Melrose, 2002, p.343)

As far as I know, I did not leave any mothers worse off after the interviews and I tried, as far as I was able, to ensure that their participation in my study met the principle of beneficence. I offered help with their situation if they needed it and, for example, shared with them my knowledge on autism. I answered their questions and provided them with Autism Centres' names and contact numbers which they might find helpful. In addition, many mothers expressed their relief after sharing their experience with me and said they found the interview to be therapeutic.

Focussed, as a therapist, on ‘Ethical Research in Reflexive Relationships’, Etherington’s (2007) work on reflexivity and the position of the researcher helped inform my study and my approach to it with particular respect to emotions: both mine as researcher and those of my participants, the ‘researched’. Etherington talks of being influenced by feminist principles relating to equality and power that challenge researchers to make transparent the values and beliefs that lie behind their interpretations and to let slip the cloak of authority, lower the barrier between researcher and researched, and allow both sides to be seen and understood for who they are (Etherington, 2007, p.600).

I have tried, here, to always acknowledge my own views and to do so, following Etherington (2007, p.600), in ways that ‘legitimize the reflexive use of “self” in research’ and doing so ethically by retaining a very conscious awareness of ‘the ideology, culture, and politics of those we study and those we select as our audience’ (Etherington, 2007 citing Hertz, 1997, p. viii). This awareness I also tried to build in to my interpretation and representations of the research stories told here and to do so in the belief, again following Etherington (2007), that my ‘self’ could be and was included in my research at all stages of this study. Ethically, following the principles of fidelity and respect, here respect for self, for me as an engaged researcher, it follows that I need to make ‘transparent the values and beliefs we hold that almost certainly influence the research process and its outcomes’ (Etherington, 2007, p. 601). It follows, too, that in this study, I need to be a researcher who has to ‘own up’ to my involvement (see Crotty, 1998) and to move away from traditional use of ‘an objective voice of the researcher to the subjective “I” ‘ (Etherington, 2007, p. 611).

In Chapter One I introduced emotions in a section entitled ‘research and emotions’ and I noted that while, to an extent, I would try to be ‘neutral’, I did become emotionally involved. It was impossible not to experience an emotional reaction to what the mothers in my study told me, both during their telling of their stories and when I listened to the recordings of the interviews. I referred, in Chapter One, to the view of Morse & Field (1995, p.78) that I might hear ‘stories of intense suffering, social injustice, or other things that will shock the researcher’ and indeed this occurred. I acknowledged, in Chapter One, that I felt uncomfortable openly sharing my own emotions with the mothers because, as a researcher, I felt I had to behave in a professional way as far as I could do so. However, while I did not want to burden my participants with my own reactions,

those reactions were a part of the research process and experience and, following the principle of fidelity and trustworthiness, it would be dishonest not to acknowledge my own emotional reactions.

In the concluding Chapter to the thesis, I note that the data collection was stressful and that the stress continued throughout the research as listening to the recordings, translating and transcribing were both emotionally and physically exhausting. I note there, too, that while subjectivity can affect objectivity in academic research (Ratner, 2002), if it were not for the personal connection and self-reflection, I would have not been able to address the participants' issues fairly. Had I ignored my emotions or the emotions of my participants I would, I believe, have violated the justice principle of treating people, myself included, fairly. However, to ensure I did justice to the voices of my participants and that, when I could so, I de-coupled emotions and experiences and data overall, then I did, of course, try to obtain a degree of objectivity in my data analysis and interpretation. I tried to make it clear, always, if I was using the actual words of my participants or if I was writing my own interpretation. That objectivity did not mean I removed myself from the study but it did mean that I tried to ensure the voices of my participants were 'louder' than my own. Moreover, I sought to ensure that my research was trustworthy and I turn now to ways in which I managed this.

As noted, in the section above on 'good research', I followed Shenton's (2004, p.64) discussion of Guba's (1981) criteria for trustworthiness and these, of course, are relevant to any ethical consideration of research such as mine. With particular respect to the principles of justice, I tried to treat my participants fairly with regard to using their words and telling their stories (credibility in the 'good research' section). Similarly, with respect to fidelity, the principle not to lie or to fabricate, then each of Guba's (1981) trustworthiness criteria was applied with the proviso that, as noted above, my data is a 'snapshot' of only some of my participants' experiences. Importantly, with regard to both the respect for persons and the fidelity principles, and again as noted above, I sought to give voice to my participants and to avoid putting 'words in their heads', 'leading' them in my interviews, and clarifying occasions when my voice, rather than participant's voices, are reproduced here.

However, another dilemma I faced while conducting the study, related to the principle of respect for persons, including their autonomy and the need to protect the vulnerable, was

the vulnerability of the mothers, due to the sensitivity of the research and I will discuss this below and return to it in my concluding chapter.

Sensitive Research

The vulnerability of the mothers was either because of the disability of their adolescents or the cultural norms and regulations they must negotiate. More often than not mothers feel vulnerable because of both the disability and the cultural norms and regulations. Silva et al., (1999, cited in Liamputtong, 2007, p.2) define vulnerable individuals as ‘people who lack the ability to make personal life choices, to make personal decisions, to maintain independence and to self-determine’. Therefore, vulnerable people include those who are ‘impoverished, disenfranchised, and/or subject to discrimination, intolerance, subordination, and stigma’ (Nyamathi, 1998, in Liamputtong, 2007, p.3), a description which fitted most of my participants, Saudi mothers in particular, who suffer gender discrimination, inequality, and unjust rules and regulations as discussed in detail in Chapter Two. As Al-Rasheed (2013, p.9) describe Saudi Arabia ‘cultural specificity, regional identities, and sectarian and tribal belongings continue as lived realities’ where religion is used as a tool to seek control over women and make them subordinate to men. Today, as I discussed in Chapter Two, Saudi women remain under the authority of their male legal guardians who control all aspects of their lives such as mobility, education and marriage. They are locked into restrictive requirements which can result in their exclusion from society. During the interviews, most of the mothers became emotional when they discussed their hurdles and struggles. Some were crying, while others seemed confused and lost. A number of mothers started crying when they talked about their sons’ future, especially when they expressed hope that their sons would die before them. Warda, a Bahraini mother, is one example:

We, as mothers of children with autism, have a sad wish: we always ask God that our children die before us! The opposite of what other mothers wish for. Because we know that no one will care of them as we do but God, so we want to be content that they are with God! No one else can handle our children and treat them well; even the fathers who do are extremely rare! I know of a mother who couldn't handle her two girls who have autism, so she jumped with both her daughters from the fifth floor to end her agony. (Warda, B)

The process of gathering such information is as Johnson & Clark (2003) state:

Necessarily involves contact with vulnerable people which when sensitive and difficult topics are often raised and sometimes raised within difficult context. (cited in Liamputtong, 2007, p.6)

Such difficulties have an impact not only on the participants, but also on the researcher. I was very moved by these stories, an account of which I give in Chapter One and Chapter Eight.

4.6 Research Procedure

The Participants

Saudi Arabia and Bahrain were chosen as the research countries because of the differences in cultural norms and laws between the two countries, and because I am originally from Saudi Arabia but I work in ‘Arabian Gulf University’ in Bahrain. As explained in Chapter Two, although both countries belong to the (GCC)⁷¹ and share many characteristics such as language, religion and many customs, Bahrain has a different approach to treating its female citizens. Therefore, the position of mothers of adolescents with autism might be better due to these differences, a view which the interviews with the mothers corroborated.

I discuss participant selection below but, in general terms, participants were chosen using a form of purposeful selection in which I sought to interview a group of women with common experiences of caring for children with autism. This is a common participant selection strategy in qualitative research and seeks cases rich in information that can be studied in great depth with respect to issues related to the purpose of the research (Thomas, 2010, p.313). For the purpose of this study, the common characteristics were being a mother of an adolescent with autism in both Saudi Arabia and Bahrain. Seventeen participants volunteered to participate, ten from Saudi Arabia and seven from Bahrain. In Saudi Arabia, the mothers were chosen from three major cities - Makkah, Jeddah and Khobar⁷², and one small town, Haddah⁷³. As for Bahrain, and since it is smaller than Saudi, no cities were specified. The target age for the adolescents with autism was from 12 to 21. The study did not specify sex as a criterion to participate. However, and as noted earlier, it

⁷¹ Cooperation Council for the Arab States of the Gulf.

⁷² Located in the eastern region on the coast of the Arabian Gulf.

⁷³ Small town near Makkah.

was difficult to reach mothers who have daughters with autism so all participants are mothers who have sons with autism.

Table 4.2 The Participants

Saudi Arabia						
Case	Name	Children	Children with autism	Age of adolescent with autism	Children with other disability	Marital status
1	Fatima	5	1	14	3	D
2	Huda	6	1	12	1	M
3	Nora	6	1	13	1	M
4	Sarah	2	1	13	1	M
5	Amal	2	1	19	1	M
6	Noha	3	1	15	1	M
7	Rasha	9	1	13	1	M
8	Nada	2	1	12	1	M
9	Mai	5	1	19	1	M
10	Rana	4	2	13/ 15	2	M
Bahrain						
11	Asma'a	2	1	20	1	M
12	Sana'a	5	1	16	1	M
13	Samia	2	1	15	2	M
14	Noor	3	1	12	1	M
15	Maha	1	1	15	1	D
16	Warda	3	1	14	1	M
17	Nouf	4	1	16	1	M

Key

M = married
D = divorced

Contacting Participants in Saudi Arabia

To collect the data, I contacted an Autism Centre in the city of Makkah that provided me with the list of names and 'phone numbers. It was during the month of Ramadan⁷⁴ when the daily routine of people changes because they focus on spiritual practices such as praying and reading the Quran. Because of Ramadan, it was difficult to arrange appointments and many mothers asked me to call again after the end of the holy month. Despite the challenges, I managed to arrange to interview all but three. The list provided by the centre only contained the mother's name, her son's name and the 'phone number without specification about age or disability. As a result, I called many mothers who had either children with other disabilities or were in the wrong age group for this study. On the 'phone, I introduced myself by giving my name, my degree and the name of the university. Then, I explained in detail the purpose of the research, what was expected from the mothers and their right to withdraw at any time during the study. At this point, I made sure that the mother was fully aware of my work and her role before I asked for a meeting. I also give them the choice of either meeting in person or conducting the interview via the 'phone, and then arranged the interview time according to their convenience. I met with six mothers in person, and had 'phone interviews with four. Five mothers were from Makkah three from Jeddah, one from Haddah, and one from Khobar. I reached mothers in Makkah and Haddah with the list the centre provided. I reached the mothers in Jeddah and Khobar through personal contacts.

Contacting Participants in Bahrain

By the time I had finished my data collection in Saudi Arabia and travelled to Bahrain Ramadan was over, so I did not face the same issues that I had in Saudi. As in Saudi, I contacted an Autism Centre in Bahrain where the social worker connected me to one of the mothers responsible for the mothers' social network who happened to have an adolescent with autism herself. I called her and explained in detail the purpose of the study, and arranged a meeting. After the meeting, she provided me with the numbers of other mothers who had sons with autism within the targeted age group whom I called later, introduced myself and explained the aim of my study. I also contacted the supervisor of another Autism Centre who added me in a 'WhatsApp'⁷⁵ mothers' group. I introduced myself

⁷⁴ Ramadan is the ninth holy month of the Islamic calendar during which people fast with no food or water from sunset to sunrise. It has a significant importance since it is one of the five pillars of Islam.

⁷⁵ Texting services used in mobile phones, which replace the usual SMS texts.

through the group and gave a brief summary of my work. A few mothers showed interest, and I contacted them directly to give a detailed explanation about the study, its aim and their roles. Just as with the Saudi mothers, I gave them the choice of either meeting in person or conducting the interview via the 'phone, and then arranged the interview time according to their convenience. I met four mothers in person, and had 'phone interviews with the other three.

During the process of contacting mothers to arrange for appointments, I was faced with many difficulties. To collect information I depended on a list of names I received from the Autism Centre in Makkah, and from personal contacts in Jeddah and Khobar; the three cities where the study took place. The list the centre provided was not up to date. Some individuals on the list had other disabilities such as Down Syndrome and Intellectual Disabilities. I chose a number from the list, called to introduce myself and explain the work I was doing. The mother would explain that her son/ daughter was not autistic. Some ended the call at that, and others asked if I could work with their children regardless of the disability. I had to apologise since my work only focused on autism. Although children with different disabilities all need special attention, each has its own teaching method, diagnosis procedures and different types of therapies. Being specialised in autism, I only targeted mothers who have children with autism and not any other disability. Other mothers were not in the targeted age group of the current study. There were other, sensitive issues. For example, one mother waited for me to introduce my work and myself before telling me that her son had passed away two years ago. I apologised and ended the call. In another case, the father answered the call and explained that the mother, who was not Saudi Arabian, had left both him and his son, had gone back to her country and was refusing to return. In a different case, the father also answered the call and said that the mother died and that his son lives with his brother where his sister-in-law takes care of him.

In a couple of cases, the fathers refused to pass the 'phone to the mothers since participating in the study would not benefit them. *'Why should we help you? What is in it for us? This is just another PhD paper and our children will not benefit from it.'* In yet other cases, the mothers would get excited about my work, arrange appointments only to cancel them, and so we never managed to meet. This was time consuming and distressing. In one case, the mother started crying *'Because of the centres' situation in Saudi Arabia I*

had to send my son all the way to Jordan. They are the reason we are separated. I will never forgive them. ' I asked her for a meeting but for a variety of reasons, the meeting never took place.

It was hard to find mothers of girls with autism. I managed to contact one mother and after giving me an appointment, she called and cancelled. Autism as a disorder that seems to affect boys more than girls (there is research which now shows that autism in girls may be underdiagnosed) which is one reason why is it hard to find such mothers (Kanner, 1943; Brugha et al., 2007). However, another reason is that girls' mothers are, perhaps, more sensitive about discussing their daughters because both societies have very traditional views of girls. Two mothers in Bahrain shared their views with me about their friends who have girls with autism.

It would be hard to meet with mothers who have girls with autism because they are usually sensitive towards such topics. A mother with a girl would find it hard to discuss her daughter's puberty, and the change of her behaviours as an adolescent. Many mothers I know try hard to avoid this topic.

One father started shouting at me when I mentioned the Centre's name because his son had been excluded from it. In two cases, the mothers knew I was working with autism, but they chose not to tell me, arranged appointments, and came thinking that they may gain financially. Many of the mothers I contacted came from a poor financial background and were struggling with money, so when I explained my study and what I did, they decided to participate thinking that I might offer them financial help knowing their situation. Of course, I could not help them financially.

When I contacted the supervisor in Bahrain centre, she added me to two 'WhatsApp' groups, one was for mothers in Bahrain and the other was a mix between Bahrain and Saudi. By the time I completed the interviews in Saudi Arabia, I saw this as an opportunity to meet more mothers. However, the group I was added to was all Shia⁷⁶ Muslims who usually live in separate areas and it was difficult to visit the Autism Centre in such areas

⁷⁶ Another branch of Islam that differs with the Sunni branch. Whereas the Shia believe that the Prophet Mohammad anointed Ali bin Abi Taleb as his successor, Abu Bakr got the title after the Prophet's death and this created the conflict since the Sunni believe that Abu Bakr was the rightful leader to take over after the Prophet.

because of the conflict between the Shia and Sunni groups, in which mistrust and lack of cooperation is, unfortunately, common.

The Interviews

First I agreed with the mothers on the place, time and method of the interview (face-to-face, 'phone). Then at the beginning of the interview, and after I introduced myself, I showed my appreciation to the mothers for agreeing to participate in the research. I started the interview by explaining to the mother that I was there to hear her story with autism, how and when it started, and her feelings towards the whole experience. All the mothers agreed to be recorded after assuring them that the recorded data would only be used for research purposes and I would be the only person to listen to it. A few mothers were concerned about having their voices recorded so I had to reassure them that I would be the only one listening to the recording and that all data would be destroyed once the research was completed. One mother wanted to ask her husband's permission, but she could not reach him so she agreed to the recording after I promised I would be the only person listening to it. Like the Saudi mothers, Bahraini mothers agreed to having the interviews recorded though I still had to assure them of confidentiality. To record the interviews, I used two devices; a digital audio-recording device and my i-Phone. I also tried to ensure a quiet setting, but because I met some mothers in public places there were outside noises that had a minor effect on the clarity of the recording.

When I talked to the participant, I explained that I was only there to talk to her about her journey with autism, and that I would not be asking specific questions, but would, rather, listen to her story whichever way she chose to share it. I explained, too, that I would use prompt, or informal and unscripted, questions during the interview to cover the key points of the research questions, and to keep the conversation flowing. Further, to make sense of the data, I used some of the strategies Miles & Huberman (1994) developed to generate meaning from data collected by interviews such as counting frequencies of occurrence (of ideas, themes, pieces of data, words); clustering, (setting items into categories, types, behaviours); and classifications and identifying and noting relations between variables' (cited in Cohen et al., 2001, p. 368)

For the face-to-face interviews, I mostly met the mothers without the presence of their adolescents with autism. However, three Saudi mothers brought their sons to meet me. In one case - Rasha - I witnessed a tantrum when Sami's nephew annoyed him. He came to the room where his mother and I were sitting and chatting and started shouting and breaking coffee cups. Rasha was in control though. She shouted at her daughter to take her son and leave the room and physically tried to stop Sami from breaking things. She managed to calm him down and took him to his room. She explained:

My situation is always like this. I need to be alert at all times. Small things irritate Sami, sometimes without me realising it. One time we were sitting in the living room having coffee, and suddenly Sami came out from his room in distress screaming and broke everything. I did not know what had happened to make him act this way - perhaps one of the programmes in his iPad had been deleted. I struggle with everything. I cannot even change my helper because Sami has got used to her, and no other helper will tolerate his behaviour. Sometimes, she decides to leave and disappear for a few months. I have to wait for her when she does and I cannot get anyone else. Once I tried to get another helper but she got scared from Sami especially when he gets his tantrums, which he gets quite often. (Rasha, SA)

I used the previous quotes as an example of the daily difficulties mothers face when caring for an adolescent with autism and the level of emotions they reveal during our conversations. During the interviews I encouraged mothers to speak freely about what they believed was important, how they felt about autism, the support they were receiving or the lack of it, and what, from their point of view, was the best way to improve their and their adolescents' situations. I used different types of questions during the interviews such as direct questions, for instance: '*When did you notice that your son's behaviour was different?*' and '*Who was the most supportive person to you during your journey?*'. I also used probing questions, such as '*Could you tell me more about the support you were receiving?*'. Indirect questions were also important. For example, '*What do most people around you think about autism?*'. I was also observant of mothers' behaviours during the interview, their body language, and how they reacted to certain questions. As I mentioned earlier, I met with some mothers face-to-face and some by 'phone. While conducting the interviews, there were no noticeable differences between the responses given by mothers using either approach. Nonetheless, there will of course always be some differences between telephone and face-to-face interviews. For example, I was unable to see my telephone respondents and so was not aware of any non-verbal communication, any body language, they were using. Comparing four different interview techniques, Opdenakker (2006) notes the reduction of

social cues via body language but he acknowledges that the social cues of voice and intonation still pertain. So, too, he suggests that in a face-to-face interview, ‘interviewer and interviewee can directly react to what the other says’ and he claims this ‘leads to the advantage that the interviewee is more spontaneous in his [sic] response and does not deliberate too long’ (Opdenakker, 2006, p.4). In my telephone interviews I may not have been able to react to the mothers as spontaneously as in face-to-face interviews but I tried to provide as much reaction, by way of encouragement to talk more if mothers wanted to do so and by allowing each participant time for deliberation.

4.7 Data Analysis

Converting conversations: translation and extract transcription process

Although it is time consuming to translate and transcribe the data, recording the interviews was vitally important for many reasons (Bryman, 2012). It would be difficult to remember all the details the mothers shared, and it allowed me to focus on the mothers since eye contact and proper interaction is crucial in these settings. Further, the topics we discussed were sensitive with mothers sharing their powerful stories which required and deserved my full attention. Throughout the data analysis process, I listened to the recorded interviews many times to bring me close to the data and to ensure I was fully aware of the mothers’ feelings and expressions. I was also anxious not to miss any detail. The interviews lasted between 40 minutes and almost 3 hours; and many mothers were quite emotional while talking about the difficulties they faced and I have discussed this briefly in Chapter One and I re-visit it in the final chapter. It was difficult to remain neutral and unbiased during the process of listening and transcribing the data. The mothers’ stories were emotional and personal, and difficult to listen to without feeling enormously stressed by their struggle and suffering. However, I was trying my best not to show my emotions during the interviews.

Although it is common in academia to give the data to someone else for transcription, I did all the translation and the transcription of extracts⁷⁷ myself for several reasons: the sensitivity of the data, to be certain that all the important details were mentioned, and to avoid outside influence on the data analysis later on. I had also promised not to let anyone else listen to the recordings. I listened to each interview immediately after I returned home and I did this to check that I had not, for example, been leading my participants or

⁷⁷ I provide a sample in Appendix Two.

interrupting them before they had finished talking. At this stage I wrote nothing about the interviews and did not start translating or transcribing the data. After completing all 17 interviews, I then, with the first four interviews wrote out the entire interview in Arabic, listened to it again and compared it to the written text. I then translated the interviews from Arabic into English, listened to it again and compared it to the English text, making additions and corrections as necessary. At the translation stage of the four interviews, I did not translate in the order of the interview but re-arranged the data according to the themes and sub-themes noted earlier and explained in more depth later in this chapter.

Additionally, I started, at this point, to summarise the words of my interviewees and to directly translate only selected extracts. It is important to note, however, that I omitted nothing from the interviews. When some participants talked about things that went beyond or were not immediately relevant to my study, I noted this in a section entitled ‘personal information’ for each interviewee. For example, Rasha (SA) talked about her upbringing as the daughter of a tribal head, a previous marriage and pregnancies, and the selling of land. These details were summarised in the personal information section of Rasha’s notes but have not been used in the thesis.

Having undertaken this process with the initial four interviews, I then modified my approach, aware that it would take months to transcribe and translate every word of every interview. So, at this point, I listened many times to each recording and then summarised the data in my own words but with some verbatim extracts that were translated as accurately as I could manage from my interviewees according to the themes and sub-themes. The key themes covered autism, including pre-diagnosis and diagnosis and social support, including spouse support, family, hospitals and schools. Further, I identified sub-themes by distinguishing between differences and similarities among the participants’ asking, for example, how many of the mothers had talked of feeling confused before or after the diagnosis of autism. I repeated this procedure with each interview. I ended up with 17 sets of notes and extracts of between 5000 and 8000 words for each case in Saudi, and between 2000 and 4000 words for the Bahraini cases.

Identifying themes is essential for data analysis. King (1998, p. 25) explains themes as a ‘pragmatic tool to help the researcher produce their account for the data and arise from engagement with the text as he or she attempts to address a particular research question’. Ryan & Bernard (2003, p.1) describe themes as ‘abstract, often fuzzy, construct which

investigators identify before, during and after data collection'. For my analysis, the data was observed for patterns and themes. To identify sub-themes I used NVivo⁷⁸, which helps assist in recognizing sub-themes by specifying connection in the interviews. I entered the fully translated transcripts into NVivo⁷⁹, and used the software as an organising tool to categorise data into themes and sub-themes.

Thematic analysis

I used thematic analysis since such analysis 'allows the researcher to process and condense raw, arrange written data into categories, which themes and categories emerge from raw data by careful examination and constant comparison' (Berg, 2001, in Plant, 2011, p.118). Thematic analysis is the most commonly used method in qualitative data analysis approaches for identifying, describing and interpreting themes to offer 'thick descriptions' of lived experience (Braun and Clarke, 2006, p.79). There are six stages of thematic analysis, according to Braun & Clarke (2006), and which I followed:

First, to become familiar with the data, I listened to and re-listened to, and read and re-read, the data many times. The time I spent in translating and transcribing the interviews allowed me to become conversant with the mothers' stories.

Second, to establish initial codes I had originally collected the data according to what I thought might be relevant phases, themes and subthemes to help me answer my research questions and so I used a deductive approach. For example, I created a table in which I listed all the things I wanted to know about caring for adolescents with autism in a traditional, sex segregated society such as Saudi Arabia and a more liberal society, Bahrain. The questions I wanted to ask at this stage included when the mother noticed her son's different behaviour, how she felt about these behaviours, when her son was diagnosed with autism, and how the mother felt about his diagnosis. So the initial themes included when the behaviours became noticeable and reactions to the diagnosis. Then, I asked the mothers about the adolescence stage, what changes she faced if any, and if taking care of her son became harder or easier. In addition, at this initial stage I asked the mother about the support she had received during her journey with autism, who she felt supported

⁷⁸ Computer software for qualitative research, which helps to organise and analyse the data.

⁷⁹ I provide an NVivo chart for one of the cases in Appendix Two.

her the most, the different types of support either from family and friends or from institutions, and how people around her reacted to her son's condition. Then, I raised questions about society in order to understand how social restrictions affect mothers' ability to care for and support their adolescents with autism, and included questions on society's attitudes, awareness, rules and regulations.

Third, and with regard to searching for themes, I used NVivo 11 software as an organising tool to arrange the data according to themes and subthemes. I entered the translated data into the software, and created nodes by careful reading and examining of each item, such as autism, informal, formal and society support, and so on. I then created subthemes from the data such as mothers' awareness, and mothers' affective responses, and compared them to all 17 interviews to ensure they were consistent and coherent.

Fourthly, and in order to review the themes, I checked the nodes I created using NVivo many times against the data to make sure it was organised logically and that all the information belonged to the appropriate themes. With continued discussions with my supervisor, and going back to both the raw material and the translated-transcribed interviews, I regularly reviewed the data according to themes and subthemes.

Fifth, to define and name themes then during the stages of searching and reviewing the themes, themes and subthemes were named and identified. For example, mothers' reactions to autism were identified as 'behavioural responses', and their feelings about their sons' conditions were identified as 'affective responses'.

Finally, to produce the 'report', the final themes were interpreted and verbatim quotes from the participants were used to illustrate and explain the themes and subthemes. I added to this using the Capability Approach, as I will briefly now discuss (with a full account in Chapter Seven).

The Capability Approach

As noted earlier, I had decided to apply Nussbaum's Capability Approach (CA) in order to better understand some of the data that pointed to underlying cultural behaviour and related social support. Using this approach I evaluate the multiple dimensions of social support, mothers' struggle with cultural rules and regulations, including gender discrimination, and unjust laws. As outlined in Chapter One, the CA as conceived by Nussbaum (2000, 2006, 2011), is a partial theory of justice that focuses on the real situation of people, on the reasons why they have an unequal ability to make use of the resources theoretically available to them. Capability development is:

The account we strive for, in which it should preserve liberties and opportunities for each and every person, taken one by one, respecting each of them as an end, rather than simply as the agent or supporter of the ends of others. ... Each person has just one life to live, not more than one. ... If we combine this observation with the thought ... that each person is valuable and worthy of respect as an end, we must conclude that we should look not just to the total or the average, but to the functioning of each and every person. (Nussbaum 2000, p. 55)

More detail of the use of the CA to analyse the data is explained in Chapter Seven.

4.8 To Sum Up and Move Forward

In this chapter, I presented the methodology used for this study. The chapter began by stating the objectives set for the study, where it was conducted to explore the journeys of mothers who have adolescents with autism in both Saudi Arabia and Bahrain. After a thorough reading of similar research, and careful consideration the qualitative research, the interpretive method was adopted in order to seek a better understanding of the mothers' situations. Further, and after explaining the research objectives and research design, the research questions were developed according to the relevant themes, these included autism and social support. Next, the ethical issues were taken into consideration by approaching the ethical committee at the University of Glasgow to receive approval for conducting the study. Followed by the research procedures, the participants and the research tool were discussed. The data was collected using semi- structured interviews. Finally, NVivo was used to organise themes emerging from the data. The detailed analysis of the data and the findings will be presented in the following chapter.

Chapter Five: Autism - A Thematic Analysis

Through the blur, I wondered if I was alone or if other parents felt the same way I did - that everything involving our children was painful in some way. The emotions, whether they were joy, sorrow, love or pride, were so deep and sharp that in the end they left you raw, exposed and yes, in pain. The human heart was not designed to beat outside the human body and yet, each child represented just that - a parent's heart bared, beating forever outside its chest.

Debra Ginsberg, cited in Otorkpa, 2014, p.60.

5.1 Introduction

As Ginsberg states above, mothers' love towards their children is like nothing else in the world, each child is a parent's heart beating outside her body. Despite the pain, distress and negative feelings that accompany the journeys of the mothers in my study, their care and affection were powerful and strongly demonstrated during the interviews. From our conversations, it was very clear that they were devoted mothers who invested significant time and effort in their sons and I try not to undervalue those experiences when I present the findings in this chapter. The findings were developed using a thematic analysis of the mothers' interviews in both Saudi Arabia and Bahrain and were organised into two main themes, autism and social support. This chapter will discuss autism in particular, the data for which is organised into three different phases: 'pre-diagnosis phase' including misdiagnoses, 'immediate phase after the diagnosis', and 'post diagnosis including manifestation of autism and adolescence phase' with a set of sub-themes such as mothers' affective and behavioural responses under each phase. These themes and their order structure this chapter.

5.2 Autism as a Broad Theme in Saudi Arabia and Bahrain

Based on the themes identified before the data collection (and which framed the interview questions (see Chapter Four), and on the data from the interviews, I categorised autism under the following phases: 'Pre-diagnosis including misdiagnosis', 'immediate phase after diagnosis' and 'post diagnosis including autism manifestation and adolescence phase' (see Table 5.1) in order to begin exploring the kinds of support available to mothers. I then further organised the data according to the mothers' 'awareness of autism', their 'affective responses', 'mothers' interpretations of their sons' behaviour', 'behavioural responses' and 'manifestation of autism' post data (see Chapter Four for how I decided on the

categorisation of the themes). I will begin the presentation of the findings by exploring Saudi and Bahraini mothers' reactions to and experiences of their child being diagnosed with autism. In the interviews, I asked the mothers to share with me their journeys with autism by engaging them in conversations about when they first noticed their sons' 'different' behaviours, their feelings and interpretations of those behaviours and, finally, their reactions towards these behaviours. I move next to discuss the immediate phase after the diagnosis, the period after their sons diagnosed with autism, and I cover the same order of subthemes outlined above. For reasons of space, and to avoid repetition, I will not discuss all of the data but will select representative extracts that strongly reflect the theme under discussion to discuss the experiences of the mothers with respect to the main themes.

Coming through the data below, with particular respect to mothers' responses to their sons' autism are numerous extracts that seem to suggest that the mothers in this study are frequently talking from a medical model stance towards disability. In the next Chapter, on social support, I note similar traces of comments related to the social model or, rather, to a lack of understanding, awareness and support that we would expect to find if the social model of disability had been prevalent. I noted, in Chapter Three, that I did not address the issues of terminology with my participants and I did not use the terms medical or social model. However, and as evident particularly in this Chapter, the mothers in this study talked often of the negative impact of ASD and they frequently referred to their sons' autism in medically deficit terms using words such as 'problems' and 'disorder'. Additionally, a number of the mothers here talked of 'treatments' and 'cures' and their responses suggest that autism has predominantly negative connotations, with an implication that autism is something for which a cure could and should be sought. So, too, the data shows some mothers looking at autism as a disability, a problem caused by something, which they tried to understand and a problem requiring medical care involving treatment and rehabilitation (see Mitra, 2006, p.237).

Table 5.1 Autism as a Broad Theme, Phases and Subthemes

Main theme: Autism	Sub-themes			
Phases	Mothers' awareness	Mothers' interpretation	Mothers' affective response	Mothers' behavioural response
Phase one: Before diagnosis of autism including misdiagnosis	Yes	Yes	Yes	yes
Phase two: Immediately following the diagnosis of autism	Yes	No	Yes	yes
Phase three: Post diagnosis including manifestations of autism and adolescence phase	Yes	Yes	Yes	yes

Phase One: Pre-diagnosis Phase Including Misdiagnosis

The pre-diagnosis phase refers to the phase before any of the mothers understood what Autism Spectrum Disorder (ASD) was or knew their sons had it. This part of the discussion outlines the data according to four themes: mothers' awareness, mothers' affective responses, mothers' interpretations and mothers' behavioural responses.

Mothers' Awareness

In the pre-diagnosis phase, all the mothers interviewed were aware of their sons' 'different' behaviours, such as lack of communication, aggression and lack of social interaction (as summarised in Table 5.2 in Appendix Five), and the categories in the data were ordered in all of my working tables according to the frequency of the behaviours.. The behaviours that seven Saudi mothers spoke about such as 'unusual playing patterns', does not necessarily mean that mothers in Bahrain did not experience similar behaviours (see Chapter Eight for limitations of the study); rather that for this particular group of Bahraini mothers, unusual

playing patterns were not so prominent as, for example, ‘sleeping disorders’. This point applies to all of my data. Just because a mother did not say something does not mean that did not happen or that she did not think it. Further, my goal here was not to pinpoint the characteristics of autism but to explore mothers’ awareness of their sons’ different and unusual behaviours.

Mothers in both countries reported that they had observed some similar behaviours such as ‘lack of communication’ or ‘loss of communication skills’. Five mothers reported their sons making what they described as odd noises and eight mothers reported sleeping disorders. Six mothers in Saudi Arabia reported that their sons had acted differently from their elder siblings. Noha, for example, describes how Khalid’s behaviour was different. *I have other children and I always thought to myself, ‘what is wrong with my son and why is he acting differently from his siblings. (Noha, SA)*

Sana’a, a Bahraini mother, reported the same experience: *‘I have 3 children before Saleem, and it was obvious that he had a problem’*. The use of words such as *problem* and comparisons with what was seen as *normal* was very frequent in the data, hence suggesting that while models of disability were, understandably, not mentioned by the mothers in my study, their language nonetheless frequently reflected that of the medical model as noted above and outlined in Chapter Three. So, for example, one Saudi mother, Sarah thought that the way her son acted *was normal* because her husband is autistic:

I was always at home with Maher and my husband. Since their behaviours are similar, I thought I was the weird one. When I started to leave the house after getting my job, I realised that my behaviour was normal and Maher and my husband were different. (Sarah, SA)

Rasha, a Saudi mother, reported a sudden change in her son’s behaviour that, in this extract, marked a switch from normal to ‘different’:

Sami was a normal child. He used to respond to me and answer me when I talked to him. It all started when he was about two years old. Loud voices started to bother him, and he began covering his ears. Also he would go into a tantrum when his routine changed. He

played in a weird different way. I have other children, and Sami was definitely very different from his siblings. (Rasha, SA)

Asma'a, a Bahraini mother shared a similar experience: *'My son was a typical child and then suddenly his behaviour changed'.*

Warda, another Bahraini mother, described a similar experience with Taher's sudden change:

Taher was a typical child until he turned a year and a month old; then the changes started. He also used to speak, and he had normal eye contact. It seemed as if Taher went to bed a typical child, and woke up as a child with autism. He lost his eye contact; lost his speech; became hyperactive; and started having sleeping disorders, sleeping only 4 hours a night. Everything happened so suddenly as if you took away Taher and brought another boy in his place. (Warda, B)

Rana, a Saudi mother, who has little support from her husband (see Chapter Six), describes Yazeed's behaviour as follows and it is noteworthy that this behaviour, similar to other behaviours mothers describe here, is regarded as deficit, perhaps exemplifying the medical model with Yazeed's behaviour categorized here as 'odd'.

Yazeed's behaviour had been a bit odd since he was a little baby. For example, he wouldn't respond to voices and wouldn't cry when he felt hungry. When he turned a year and a half, he started saying 'mama', 'baba' and other simple words which he lost later on. He had very limited communication, and played in an odd way. He would do weird things like line up all our shoes, and come to the kitchen for plates and start spinning them. He would accept strangers, and did not mind if a stranger picked him up. I was comparing him to his older sister. For example, when some stranger tried to carry my daughter she would cry and scream. At that time, I thought this was a good thing. I was thinking to myself "My son is sociable and he likes people". (Rana, SA)

Yazeed is displaying some of the common characteristics associated with ASD: limited communication and social skills, and obsessive behaviours (Russell et al., 2005), as I explained in Chapter Three. However, in both Saudi and Bahrain some mothers reported that their sons acted like 'typical' children but then they suddenly lost their social and vocal skills. Warda, a Bahraini mother, for example, described Taher's sudden change:

Taher was a typical child until he turned a year and a month old; then the changes started. He also used to speak, and he had normal eye contact. It seemed as if Taher went to bed a typical child, and woke up as a child with autism. He lost his eye contact, lost his speech,

became hyperactive, and started having sleeping disorders, sleeping only 4 hours a night. Everything happened so suddenly - like you took away Taher and brought another boy in his place. (Warda, B)

In order to explain their children's 'strange' and 'different' [not normal] behaviour, such as repetitive behaviours (see Boyd et al., 2012), two Bahraini mothers (Asma'a and Noor) believed that their sons were affected by the Measles, Mumps and Rubella vaccine - MMR⁸⁰, in which the vaccine caused their sons' disorder. Anjali et al., (2015) examined a large sample of children in the US – 95,727 children - and found no harmful association between receiving MMR vaccine and Autism (see Chapter Three) but this does not, of course, mean that people will stop believing that MMR could cause autism. So, too, resonating with an implicit medical model, this 'explanation' looks to find a medical explanation for autism as a medical order that could, perhaps, be explained if not 'cured'.

With respect to other disabilities, two Saudi mothers have more than one child with a disability or autism, and one Bahraini mother has a daughter with an intellectual disability in addition to her son who has autism. Fatima, from Saudi, has three disabled adolescents: a girl with intellectual disabilities, a boy with autism, and another girl with a visual impairment. Rana, a Saudi mother, has two adolescents with autism. Because of her experience with her first autistic son, she noticed her second son's different behaviour and immediately identified autism. Samia, from Bahrain, has two disabled adolescents, a son with autism and a daughter with severe intellectual disabilities. According to Orsmond et al. (2007), mothers who have more than one disabled child usually have increased stress levels and report higher depression and anxiety, which accords with the stories of the mothers in my study. A number of the mothers talked about the difficulties of bringing up one child with autism, especially when support was lacking (this was Rasha's experience, for example as discussed in Chapter Six). The mothers who have more than one disabled child reported higher levels of stress which made it harder for them to access support from, for example, their husbands who tended to pass the burden of care to their wives, as I will explain in Chapter Six. Rana, for example, struggled with two boys on the autism spectrum

⁸⁰ Much research has discussed the link between autism and MMR vaccine, how the disorder can be activated by taking the vaccine, yet they found no link between them (Rao & Andrade, 2011).

and this negatively affected her and her relationship with her husband. I will discuss now mothers' affective responses toward their sons' different behaviours.

Mothers' Affective Responses

During this pre-diagnosis phase, most mothers had not yet been introduced to the term 'autism' (see Table 5.3 in Appendix Five). While the feelings among mothers toward their sons' different behaviours were similar in both countries, a feeling of confusion was dominant. Nine mothers from Saudi and four from Bahrain said they felt confused by their sons' behaviours since they had not experienced autism previously, and this is a common feeling that occurs for new parents of children with autism according to Stillman (2008).

While the mothers did not always specifically name the emotion they felt, it is apparent from their accounts that they were worried, lonely, anxious, felt fear or guilt, or suppressed their emotions in order to cope (see mothers' affective responses below in 'Diagnosis' for further discussion) and this matches the views of Dunn et al. (2001) who state that stress and fear are frequent when dealing with diagnoses of autism. Nada, who works in an Autism Centre, and who understood the reason for her son's behaviour, still felt a mixture of fear that her son had autism, and denial since she did not want to believe the obvious, as she describes below:

The fear that Adel has a problem never left me. Yet, every time I try to talk to someone about it they say I have become doubtful and suspicious from working in this field (autism). Since I am a mother, and I want my children to be perfect, I would ignore my feelings and listen to them hoping I was only imagining things. I was in denial. (Nada, SA)

Nada's identification of Adel's 'problem' points, again, as do further extracts here, to the medical model although Nada seems not to expect a 'cure'.

Another Saudi mother, Nora, felt confused and distressed about her son's behaviour. As she explained:

Ahmad used to cry a lot and I had no idea what was wrong with him. I did not know what to do or what to give him to make him feel better; all I could do was to cry with him. (Nora, SA)

Similarly, many Bahraini mothers knew that their sons had problems before the diagnosis. Maha, for example, told me that she and her husband:

Visited so many doctors back then and they all said that Amir was ok yet I always had the feeling that something was wrong with my son. (Maha, B)

Just like the mothers in my study, evidence shows that parents' early concerns often predicted their sons' developmental problems such as autism (Zuckerman et al., 2015). As for now I will discuss how the mothers interpreted their sons' behaviours.

Mothers' Interpretations of Their Sons' Behaviours

As most mothers had never experienced autism, they tried to make sense of it by interpreting the behaviour as resulting from jealousy, poor attachment, or hearing problems. Children on the spectrum often do not respond when they are called, leaving mothers to think they have hearing issues (Wiley et al., 2014). However, one mother in Saudi (Nada) and three mothers in Bahrain (Maha, Sana'a and Nouf) thought their child's behaviour could be caused by autism. In other cases, mothers simply did not know how to account for the behaviour of their sons although they tried to find an explanation, again pointing to elements of an implicit medical model (see Table 5.4 in Appendix Five for details).

Mai, a Saudi mother, thought that someone was frightening her son: *'When Rami started showing these symptoms, I thought someone was scaring him; perhaps the helper, but after that I felt that these actions were just not normal!'* (Mai, SA)

Warda, a mother from Bahrain, reported that though people pointed to the 'evil eye'⁸¹, she did not really believe in it:

Since everything was so sudden, people around me were coming up with different theories such as that Taher was obsessed with an evil spirit, or someone had given him a black eye, but I did not believe in these things. At that time, I was confused, and I didn't understand what had happened to my son all of a sudden. (Warda, B) In the coming section, I will discuss mothers' behavioural responses toward their sons' different behaviours.

Mothers' Behavioural Responses

Each mother reacted differently to her son's behaviour. Demonstrating responses related to the medical model of disability and the need to find a 'cure' for their sons, one resorted to prayer. Interestingly, there is some evidence of a positive association between spirituality

⁸¹ The 'evil eye', also known as 'a black eye', refers to the harm (physical or physiological) someone could cause by looking with envy or jealousy at what someone else has.

and a decrease of negative feelings (Gallagher, et al., 2015) but there is no evidence that prayer will ‘cure’ autism. Other mothers contacted hospitals, schools and autism centres with questions and requests for help (see Table 5.5 in Appendix Five).

Fatima had previously lived with an abusive husband (see Chapter Six). When she divorced him she was denied access to her children for many years. She always prayed to God for her children’s salvation and survival from their abusive father: *‘I was always asking God to bring my children back to me’*. When they ran away and found their way to their mother, Fatima managed to take her son to hospital where he was diagnosed with autism.

Other mothers believed that taking their children to Autism Centres would resolve their problems, a behaviour many mothers resort to when need of support according to Weiss (2002) and, again, behaviour that reflects an implicit medical model focussed in treatment or rehabilitation, as outlined in Chapter Three. Huda sent Ali to many schools but they always asked her to take him away because of his difficult behaviour. One of the pre-school Principals suggested she take her son to an Autism Centre, which she did and which later diagnosed Ali’s autism. Huda also believed that money would help the problem: *I knew how difficult Ali’s behaviour was, and I told the preschool that I was willing to pay double the fees if they would keep him and not ask me to take him out. (Huda, SA)*

Rasha, like Huda, also took Sami to an Autism Centre on the advice of friends and neighbours, which also helped determine his diagnosis. Sarah worked in a private university with a special education department. When she described Maher’s behaviours to some of her colleagues she was told he had ADHD, prompting Sarah to start reading about it. However, she always felt that Maher’s differences stemmed from something else. Because he had nightmares from playing video games, Sarah took Maher to a psychiatrist who suggested autism. Here she expresses frustration as well as anxiety for the well-being of her son:

He would scream suddenly saying that his sister had started bleeding, or that my neck had been cut off. I would then shout at him and ask him to open his eyes. I got worried and took him to the doctor. (Sarah, SA)

During this phase, and as noted earlier, mothers did not know that their sons had autism, and tried to make sense of their different behaviours through personal interpretation such as

hearing problems or possession by evil spirits. As shown in the data, all mothers had negative feelings such as confusion and loneliness during this phase in which some sought medical help while others tried Autism Centres. In the next phase, I will discuss the misdiagnosis of autism.

The Misdiagnosis Phase

I have included 'misdiagnosis' as part of the pre-diagnosis phase since it occurs just before the diagnosis during which some mothers come to understand their sons' behaviours either by going to hospitals or schools for formal support and advice (see Chapter Six for further discussion). During this phase, some mothers (five in Saudi Arabia and two in Bahrain) received an accurate diagnosis of autism, while others did not (see Table 5.6 in Appendix Five). Even though some mothers expressed their feelings toward the misdiagnosis and whether they believed it or not, the focus was on the official diagnosis they received at this stage.

Five Saudi mothers and five Bahraini struggled to obtain a correct diagnosis for their sons as indicated in Table 5.6 (Appendix Five). This is a struggle encountered by many parents of children with autism according to Varma & Iskandar (2014). The misdiagnoses the mothers encountered included ADHD, hearing issues, separation anxiety disorder and intellectual disability. Nora, for example, went to many hospitals before Ahmad was diagnosed with autism (see Chapter Six). The sons of Mai (a Jordanian mother who lives in Saudi) and Maha (Bahrain) were diagnosed with intellectual disabilities, a diagnosis that Mai rejected:

Something inside me kept saying that my son doesn't suffer from an intellectual disability. I continued to ask around and talked to the Principal of the centre where Rami goes. She suggested I look into autism and recommended a good centre where I could take Rami.
(Mai, SA)

Maha doubted her own capacity to assess what was wrong with Amir but she knew something was not quite right:

I read a lot about autism and I felt that Amir had it, but I am only a mother not a specialist; all I had were my feelings toward my son. So I used to say to myself, "Maha what do you know? If the doctor said your son has an intellectual disability he knew better" (Maha, B)

Next I discuss how mothers reacted when they received the diagnosis of autism.

Phase Two: Immediately Following the Diagnosis of Autism

This phase occurs immediately after mothers received the autism diagnosis, and, as noted earlier, it contains four subthemes: mothers' awareness, mothers' affective responses, mothers' interpretations and mothers' behavioural responses. The duration of this phase was not specified in my interviews but, for instance, I asked 'How did you feel when you first heard the diagnosis?' I now discuss these themes.

Mothers' Awareness

Some mothers in Saudi and Bahrain were familiar with the autism disorder when they first received their sons' diagnosis, while others heard about autism for the first time (see Table 5.7 Appendix Five) and awareness of autism, after receiving their son's diagnosis, differed from one mother to another.

Mothers who had heard about autism found it easier to understand their sons' behaviour at the time of the diagnosis. In six cases, one Saudi and five Bahraini mothers had managed to connect their sons' behaviours to autism even before the diagnosis. Another Saudi mother, Nada, who I discussed above, worked in an Autism Centre and predicted her son's diagnosis before she received it officially. Pre-knowledge of the diagnosis had a positive effect on her emotions and reactions to her son's diagnosis. However, four mothers, two in Saudi (Amal, Sarah) and two in Bahrain (Warda, Noor) had heard about autism but did not connect it to their sons' behaviours.

Five mothers in Saudi had never heard about autism before (Fatima, Huda, Nora, Noha, Mai), and Noha, describes how she began to educate herself about autism in order to understand both the condition and its effects on Khalid, and to know how to manage his behaviour:

It was my first time hearing about autism, I had no idea what it meant. The doctor tried to explain the meaning of the disorder by saying "Khalid will not socialise with people, he likes to be alone, and he will not make eye contact with others". (Noha, SA)

Rasha, a Saudi mother, believed her husband's conservatism⁸² was one the reasons she did not hear about autism and was not aware of its characteristics:

We had no access to any media; my husband was a very conservative man so we did not have a TV at home. So it was like we have no connection to the outer world, which is perhaps one of the reasons I had never heard about autism before. (Rasha, SA)

Asma'a came across autism watching television:

One day, I was there watching a TV interview with a Kuwaiti⁸³ doctor who was talking about the autism disorder and describing its symptoms. The symptoms she talked about sounded very similar to Khan's behaviour (Asma'a, SA).

Next, I will discuss mothers' affective responses toward autism and here, again, there are reactions that for with the sort of attitudes we might expect to see in the medical deficit model of disability.

Mothers' Affective Responses

Mothers' feelings about their sons' diagnosis varied in both countries; some mothers felt shocked and lost, while others were relieved (please see Table 5.8, Appendix Five).

Mothers struggled with negative feelings about their sons' diagnoses such as confusion, helpless, loneliness, sadness, pain and self-blame. Huda, for example, struggled with mixed emotions in which she blamed herself and experienced frustration and hopelessness. These are common emotions experienced by parents of children with autism (Sivberg, 2002) and so, for example, Huda states:

After what they told me about Ali, I kept thinking "why me? All my other children are normal, why this boy? What did I do wrong?" I do not remember taking the wrong medicine during pregnancy or taking any x-ray! (Huda, SA)

Rana who was certain her son had ASD, and had been reading about it until he was formally diagnosed at 3 years' of age, was, nevertheless, shocked when the diagnosis was confirmed:

⁸² Some conservative families believe it is forbidden to watch television, claiming that the programmes prompt sinful behaviour

⁸³ Kuwait: an Arab country on the Arabian Gulf and it shares borders with Iraq and Saudi Arabia.

I was shocked when we received the diagnosis. I knew what autism was in general, but I didn't go into detail since my goal was to identify my son's problem rather than how to handle it or deal with it. (Rana, SA)

Rana went on to describe how she felt on receiving her son's diagnosis.

When Zaid was diagnosed, I felt like a person who had lost everything. Both my boys have autism, and there is no difference in age between them. I barely woke up from my first shock, to start going through another. (Rana, SA)

Noha was also upset:

When I first heard that my son was suffering from a disorder and that he would be like this for the rest of his life, I started crying. I did not know what else to do. I was shocked that there something like this even existed. Something called autism, and it is happening to my son. (Noha, SA)

While most mothers felt great concern about their sons' condition, Mai and Sarah, from Saudi Arabia, felt relieved when they finally received their sons' diagnoses. As Mai says:

When I found out what was wrong with Rami I felt relieved. I was happy that things were finally clear. I know what is wrong with my son, and I know how to handle it and deal with it. (Mai, SA)

As described in Chamak & Bonniau's (2013) study, some parents feel relieved after obtaining the diagnosis since they could finally name their child's condition and learn how to live with, and respond to, their child's distinctive behaviours. Interestingly, at this stage, few if any mothers suggested they might be able to call on support from the society around them but, instead, and in keeping with a medical model, that they would need, themselves, to 'deal with' and 'manage' this disorder: it was their problem not society's. Knowing the reason behind their child's behaviours meant they could start planning for effective support, both formal and informal (as I detail in the next Chapter) and, indeed, the diagnosis meant the mothers could now support their children appropriately but mothers regard their sons' autism as a trait of their sons and not as a disability understood via the social model in which the concept of disability is created by the social environment and requires that environment to change (Mitra, 2006). Here, the extracts point to the mothers themselves taking action with a view to helping their sons and expressing, often, relief that they know, now, what is 'wrong'.

Sarah says:

When Maher was finally diagnosed, I felt relieved because whatever my son was going through had a name. Now I knew what I was dealing with. I was also relieved because I was not imagining things - that Maher is actually different and all my observations were real - especially because everyone around me kept telling me that nothing was wrong, and I was making things up. But now I know exactly what my son has, and I know how to help him. (Sarah, SA)

Asma'a and Maha from Bahrain expressed similar feelings of relief. Asma'a for example, described how she felt 'a bit relieved' that she now knew what she was 'dealing with'.

Warda, on the other hand, decided not to think of her feelings:

I decided not to give way to my feelings; all I cared about was how I was going to help my son, what I could do for him. (Warda, B)

Negative feelings were dominant in this stage and few mothers felt any positive feelings such as happiness. Mothers felt relieved because the confusion was over and whatever their sons were struggling with now had a name. Arguably, knowledge means control and power, in that knowing and understanding autism might allow the mothers not to only seek the help their sons need, but also to care for them more sensitively and attentively than before. In the next section, I will discuss mothers' behavioural responses toward autism.

Mothers' Behavioural Responses

After receiving the autism diagnosis, each mother reacted differently to her son's condition. In keeping with the medical model and a focus on seeking treatment, some looked for Autism Centres, while others, as I discussed above, started reading about the disorder in order to understand their sons' behaviours and provide support for their proper care. Some mothers used alternative methods, either herbal remedies, or resorted to religious practices, as treatments for the 'disorder' (see Table 5.9 Appendix Five).

Two mothers, Warda and Noha, tried Hyperbaric Oxygen Therapy (HBOT)⁸⁴ in Jordan. Some studies support the positive affect of HBO on individuals with autism (Rossignol et al., 2012), while other studies question how beneficial is the treatment (Ghanizadeh, 2012). Other mothers used particular foods such as Mai who used soaked raisins to enhance Rami's memory and Rana who used herbal tablets to boost the immune system, and ease

⁸⁴ Hyperbaric oxygen therapy (HBOT) is a medical treatment which involve a use of 100% oxygen at pressures greater than atmospheric pressure in a closed chamber (Bhutani & Vishwanath, 2012).

her son's anxiety. Nora prays all the time for Ahmad's health as he is often ill, despite her very good care, and his ill health is a source of worry, concern and, perhaps, guilt:

I am not a bad mother and I make sure he eats well, dresses well and takes his medicines. I am very careful with Ahmad and I never neglect him or his needs. It is very hard for me to see him suffer and I always pray to God to take my health and give it to him. (Nora, SA)

Sarah, from Saudi, was one of the mothers who attended lectures to further understand her son's condition and to provide him with the support he needed:

I used to attend lectures and expeditions held by my university where I learned a lot about autism. For example, tying a shoelace is difficult for a child with autism, so I only buy my son shoes without laces so I do not pressure him into doing something difficult. So, with the help and support of my work, I taught myself how to help and handle Maher. (Sarah, SA)

Huda gave a very honest account of her treatment of her son, Ali. She resorted to violence as a means of unloading her frustration hitting Ali every time he misbehaved until one day, in desperation she decided to call the Autism Centre for help. This was Huda's second attempt to enrol Ali but lack of spaces meant the centre was unable to take him (see Chapter Six):

I called the centre again ... and started crying. I told her that me and my son were in desperate need of help. I told her I did not know how to deal with him, and if she did not accept him into the centre I was going to hit him till he died. (Huda, SA)

When she failed to secure him a place, Huda completely ignored Ali leaving him to a helper who became fully responsible for his needs and support:

At that time I completely ignored my son as if he did not even exist in my life. I always said to myself, "You have other children Huda, take care of them - they are the ones worthy of your time". (Huda, SA)

Huda seemed helpless, finding it easier to attend to her other, 'normal', children as a way to reduce stress. I tried to distinguish between affective and behavioural responses, however, they often overlap as demonstrated in Huda's case.

A number of mothers in Saudi Arabia and Bahrain used alternative methods to try to 'treat' their sons' conditions and give them necessary support in ways that fit an implicit regard of autism as a disability within a medical model. Huda, Mai and Rana (Saudi), and Asma'a, Warda and Noor (Bahrain) for example, tried the autism diet⁸⁵ since many studies had

⁸⁵ Gluten- and casein-free diet, which excludes milk and wheat products. It is believed to reduce autism symptoms.

apparently shown positive changes in the behaviour of individuals with autism who follow a gluten and casein free diet, apparently leading to improvements in communication and attention (Whiteley et al., 2012). As Asma'a explains:

I started using the food diet when Khan was about 5 year's old. I found it helpful so we have actually been on the diet since 2000. It has been 15 years and now Khan knows what to eat and what not to eat. (Asma'a, B)

Amal was in the UK when she received the diagnosis and enrolled Kareem in a special school in order to obtain the right kind of support for her son. She also used alternative methods such as healing energy, and had plans to go to India for further treatment. In terms of religious practices, Amal, Noha, Rasha and Nada (Saudi Arabia); and Noor and Nouf (Bahrain) went to Imams⁸⁶ to read the Quran for their son hoping it would improve their conditions. Rasha, however, was denied this source of support by her husband:

I wanted to take Sami to a couple of Imams to read the Quran but my husband refused and said we could do it ourselves. So I asked my neighbours for their help. They helped me by taking Sami to an Imam to read the Quran over him without my husband knowing. (Rasha, SA) Rasha, being a Saudi woman, is not allowed to drive and could not take her son anywhere herself as I discuss further in Chapters Six and Seven. In the next section I will discuss the post diagnosis phase.

Phase Three: Post Diagnosis Including Manifestation of Autism and Adolescent Phase

This phase occurs after the mothers officially receive the diagnosis of autism. The manifestation of autistic behaviours and adolescence phase are included and, in some ways, this is the phase of everything in the mother's interviews that relates to their experiences after the initial diagnosis.

Manifestation of Autism

In this section, I focus on mothers' accounts of manifestations of their sons' autism. I have not included awareness because mothers already knew something about autism since they had received the diagnosis. Neither, have I separated out affective and behavioural responses as each was so often entwined in the other. I have, however, noted such

⁸⁶ An Islamic scholar who usually leads prayers in mosques. Most Imams memorise the Quran by heart, and people usually go to them when they face issues, so they read verses of the Quran to ease the pain, or solve the issue.

responses when the mothers' words made them explicit. Autism characteristics vary significantly from one individual to another (Sicile-Kira, 2004), as explained in Chapter Three and, unsurprisingly, mothers in Saudi Arabia and Bahrain experienced similar and dissimilar difficulties with respect to their sons' behaviours. In the next section, I will give examples of the manifestations of autism with which my participants were trying to cope, usually with little or no formal support.

Non-verbal communication, communication without words, is common among individuals with autism (Stone et al., 1997). Fatima's and Samia's sons are both non-verbal, which means that mothers can struggle to understand their sons' needs.

It was hard for me to understand his needs. For example, when Sameer feels hungry he takes my hand and walks to the fridge. (Fatima, SA)

Samia's son was more aggressive: *'Fahad would use inappropriate behaviour to express his needs since he is nonverbal. For example, he would hit me when he felt hungry. (Samia, B)*

Sarah's main concern was Maher's limited social skills, which many individuals with autism experience (Hussein et al., 2011), and which often manifest in a preference for playing alone and discomfort in social settings:

Every Wednesday, the family goes to Maher's grandmother house, where so many children are gathered. Yet, Maher would stay in a corner with his toys and play alone, or he would refuse to even go and stay home. Maher was a peaceful child, he had no aggressive behaviour towards himself or others, yet he always cries when he is in crowded places or if someone tries to come close to him. I had to stop going to these gatherings. (Sarah, SA)

Another problem Sarah faced was that Maher did not realise his own strength, especially now that he had reached an advance level in Martial Arts:

Once, he was playing with his cousin and during the play Maher pushed him accidentally, the boy fall and broke his teeth. Maher was so devastated with what he had done and started crying non-stop. So I always explain to him how to control his physical strength. I tell him that if he hurts someone badly, the police will look at it as a crime and he will end up in prison. I even explained to him what prison is like, that he will not have his parents,

his entertainment or anything he has just now. I also told him that people are treated badly in prison. The reason I talk to Maher about that is so that I can live with whatever happens to him, but I do not think I could take it if he hurt someone else. (Sarah, SA)

Sarah's own fear for her son's future well-being means that she has to use fear to help Maher understand that his strength can get him into significant trouble unless he takes care with others.

Amal and Sana'a both talked of the hyperactivity of their sons, which commonly occurs in individuals with autism according to Reiersen & Todd (2014). Kareem, Amal's son, moves a lot, gets bored quickly and refuses to stay in one place. As a result, Amal, lacking any kind of support, isolated herself from her circle of friends and family:

It was hard to go out with Kareem. Even when I tried to take him places he ends up embracing himself and me. So I decided to live in isolation with my son. We both stayed home, without a social life or a circle of friends. I only have Kareem and my work. (Amal, SA)

To control their sons' difficult behaviours, Amal and Rana resorted to medication for support, though Amal 'hates chemical' medicines:

Medication is the only way to calm Kareem down. His behaviour worries me because he could get violent with other people and with himself. I do not want him to harm himself or others, that's why I felt medication is important since it keeps his behaviour under control. (Amal, SA)

Autistic children often self-harm, engage in aggressive behaviours and tantrums, sometimes for no obvious reasons. However, these behaviours can be manifestations of sensory overload, frustration and lack of sleep (Sicile-Kira, 2004). Rana's son, Zaid, began to display those behaviours from when he was about 10 years' old:

He became really aggressive towards himself for no obvious reason. He would scream and shout and hit himself nonstop until his body was full of bruises; when I tried to stop him, he ended up hitting me. He would go into tantrums and start breaking things around the house, which is why I considered medication. He would go so far as to stick his fingernails

in his hand until it bled. He also stopped talking, and wouldn't sleep more than two hours at night. (Rana, SA)

In order to control his behaviour, Rana took him to the doctor who prescribed Risperidone⁸⁷. The effects of the drug were immediate, bringing relief to both Rana and Zaid:

We started the dose with a quarter of a ml, and the minute I gave it to Zaid, he fell asleep for 9 hours uninterrupted. He calmed down and stopped hitting himself. The same situation happened to Yazeed months later even though he is older. So I just started giving him the same medicine Risperidone without asking the doctor. (Rana, SA)

In these examples we see more evidence of an implicit medical model in operation. The 'fault' is often ascribed to the autistic individual and mothers make adjustments to fit society as well as seeking treatments to 'control' the behaviour that they and others regard as different from the norm.

Lack of emotional expression is an additional common characteristic among individuals with autism (Flaharty, 2013). This, too, can make them seem 'different' and some mothers, understandably I would suggest, are concerned with such differences as these, again, mark their sons out from the 'normal' and so, again, we see an implicit medical model of disability coming through these extracts. The 'problem' is their sons' and very rarely do the mothers suggest society might need to change to accept the characteristics of autism. Kareem's lack of expression worries Amal greatly:

Kareem doesn't express his feelings. When I cut his nails for example I don't know if I am hurting him or not. Once we went fishing and the fishing hook went into his hand and he expressed no pain at all. He also suffers sensory issues, where light and noise annoy him, which causes a tantrum and he completely loses control of his reactions and behaviour. (Amal, SA)

Individuals with autism find it hard to understand the concept of danger according to the National Autistic Society (2011), an issue Noha reported:

Khalid did not understand the concept of danger. He climbed up the cupboards at home and did not fear falling down. He also let go of my hand when we walked in the middle of

⁸⁷ Antipsychotic medicine that treat schizophrenia, bipolar disorder, and irritability and mainly used for individuals with autism.

the streets and crossed without paying attention to speeding cars. He was lost before in a shopping mall because he would just let go of my hand and run away quickly, and it was hard for me to catch him. (Noha, SA)

Both Rasha and Warda faced the problem of their sons running away. Rasha said:

He used to run away from home a lot, and the neighbours would find him wandering around in the neighbourhood and bring him back. (Rasha, SA)

Rasha and Asma'a reported the importance of routine in their sons' lives in supporting them to live as normally as possible (Turner, 1999; Brereton, 2008). Rasha said:

Sami used to stay in the living room due to lack of space ... he used to arrange his toys on the coffee table in the living room, then one of the boys would remove Sami's toys from the table because they needed to use it. Such actions would drive Sami insane. He would scream, cry, and go into one of his tantrums. When he loses one of his toys, his behaviour becomes hard to handle. (Rasha, SA)

Similarly, Asma'a said:

Khan is very well organised. He arranges all his things in order. He doesn't like anyone to touch his room or his stuff. It used to annoy me but I got used to it with time. He is also keen to keep his routine. For example, every time we visit my husband's family, he sits next to a fan they have and keeps switching it on and off. (Asma'a, B)

Echolalia, the repetition of vocalizations made by someone else, as Stribling et al (2006) discuss, is another very common symptom of autism. As explained in Chapter Three, individuals with autism sometimes use echolalia to gain time to understand the conversation and take part in it (Saad & Goldfeld, 2009). It could also reflect emotions such as stress, anger and anxiety (Prizant & Rydell, 1984). This is Nada's account of echolalia:

When Adel reached a year and a half, he started to use echolalia where individuals with autism repeat voices and noises they hear. For example, he would repeat the sound of prayer 'Al'Athan' exactly as he heard it. Adel also started showing interest in odd things. For example, when he sees a table with an ornament⁸⁸ on it, he sits next to the table and does not move. If we visit some of our cousins, and they happen to have a picture of the Holy mosque in the city of Makkah or Madinah, he ignores the people, and goes and sits next to the picture and says the sound of prayer 'Al'Athan' repeatedly until I go and stop him. Adel would also hum a lot when he tried to speak or sing. He would repeat childish chants without moving his lips. (Nada, SA)

⁸⁸ Decoration added to furniture which make it look more attractive such as xylography.

Adolescents with autism also commonly experience epilepsy, as Sicile-Kira (2006) confirms, and Maha recounts:

My son would have a seizure, fall asleep, wake up with hyperactive behaviour, have another seizure, fall asleep and so on - this was Amir's life. He was dead and alive at the same time. (Maha, SA)

Mai struggles with Rami's ability to express his needs (Hutton & Caron, 2005):

Rami can speak, and he knows how to name things but he doesn't know how to express his needs. For example, he can't say he is hungry or thirsty. (Mai, SA)

Rana sought medical support from her doctor for Yazeed's difficulty in swallowing. The Doctor was unsympathetic to her plight and unsupportive of her need to help her son eat. Yazeed had reached a stage, said Rana, in which *'he stopped chewing his food - the morsel would stay in his mouth for almost three hours'*. When Rana took him to the doctor, the doctor refused to help telling her that he could not give him a syrup antibiotic because he was an adult and had to learn how to swallow. It was up to her, Rana, to teach him how: it was Yazeed's problem or, rather, it was Rana's problem and this appears again in the next section, where I will discuss the adolescent phase.

The Adolescent Phase

Adolescence is often a difficult time for most individuals and their parents during which many changes occur such as increased sexual awareness and arousal with behavioural and hormonal changes (Brereton et al., 2006). Eight mothers in Saudi and five in Bahrain faced those changes while others did not because their sons had not then reached puberty. In this section, I will cover the four same subthemes of mothers' awareness, mothers' affective responses, interpretations and mothers' behavioural responses. Mothers with adolescent autistic children find it especially difficult to obtain formal or informal support because of the embarrassment of discussing sex and sexual issues in traditional societies such as Saudi Arabia and Bahrain.

Mothers' Awareness

Some of the adolescents discussed here reached puberty, others showed changes in behaviours, while some remained the same (see Table 5.10, Appendix Five). Eight mothers in both countries, four mothers in Saudi (Rana, Sarah, Noha, Nada) and four in Bahrain (Asma'a, Samia, Warda, Nouf), reported what they felt to be inappropriate sexual behaviour such as touching oneself and others. Nada for example, noticed her son's behaviour:

He would go to his room, lie on bed and start touching himself. When I followed him into the room, he asked me to leave because he knew I would ask him to stop. Then I decided to ignore it and redirect the behaviour. I enrolled him in gyms and he learned swimming. (Nada, SA)

Rana shares a similar experience:

One time, I was wearing shorts at home, Yazeed came as usual and started touching my legs. Suddenly he started having an erection, so I got up immediately and tried to divert his attention to something else. (Rana, SA)

Asma'a and Nouf taught their sons the meaning of privacy, and to go to the toilet or stay in their own room when masturbating.

Others adolescents showed stubbornness, a tendency to break rules by arguing, shouting and crying, as reported by six mothers in Saudi (Fatima, Huda, Sarah, Amal, Rana, Nada) and one mother in Bahrain (Samia).

Two mothers, Sarah and Amal, said that their sons were not aware of their strength that had developed with age, and they were worried that their sons might hurt themselves or others without intending to do so.

Amal:

Kareem does not realise his level of strength. He moves fast and without being aware of the damage he could cause. One time, he wanted to eat a cup cake and sugar is not very good for him. So I was trying to take the cake away, and while he was trying to reach for it he pushed me away. His push was strong he broke one of my ribs. (Amal, SA)

Warda, a Bahraini mother, reported the same problem: *'Taher is physically unusually strong. He hurt me before unintentionally and did the same with his little brother'.*

Two mothers (Amal, Warda), one in each country, said that their sons became more isolated. Amal's son Kareem, for example, became more isolated from people and started to connect to animals:

The further away from people Kareem grew, the closer he grows to animals. I was helping him fulfil this passion; I hired a special trainer to help him take care of his pets. I was happy to see him doing something. (Amal, SA)

Many therapies are used as interventions to help those with autism, one of which is pet therapy. Studies have shown that pet therapy has a positive effect on individuals with autism, with improvement in communication, sensory stimulation and focusing (Siewertsen et al., 2015). Amal was not, perhaps, familiar with such research but she supported Kareem with his connection to animals.

The adolescents of Huda, Sarah, Noha, Sarah, Mai, Nada and Rana are independent enough to meet their basic needs such as using the toilet, eating and changing clothes. Independence skills are crucial during this age, in which caregivers are advised to encourage and train their adolescents with autism to learn such skills (Hume et al., 2014). Another issue concerning adolescents with autism is self-harm and, as I discussed above, some individuals with autism can engage in self-harming behaviours as well as aggression towards others (and see Singh et al., 2011). Mothers in Saudi have experienced aggressive behaviour towards self and others (Huda, Rasha and Rana), and Samia, a Bahraini mother, reported the same behaviour which she linked to sexual frustration.

Rana describes Yazeed's aggressive behaviour toward his teacher in school and his siblings at home:

One time the teacher asked to see my husband, and asked him to change Yazeed's shoes for softer ones because when Yazeed got bored with lessons, he kicked the teacher on his back while he was standing at the board. He also hit the helper at home and hit his sister. He became a rebel. (Rana, SA). This behaviour worried Rana and we see similar responses in the next section, where I will discuss mothers' affective responses toward the adolescent stage.

Mothers' Affective Responses

Mothers in both countries experienced similar and different feelings about adolescence which varied between acceptance, confusion, exhaustion, embarrassment and fear (see Table 5.11, Appendix Five). Having sons for some mothers was another issue.

Gender discrimination in Saudi Arabia is evident not only in the treatment of mothers, but also in their thoughts about having sons with autism rather than daughters. I discussed gender issues in Chapter Two in which I explained cultural norms and attitudes to women and girls. I will return to this in Chapter Eight where I note how difficult it is to reach out for mothers who have daughters with autism and who wish to believe that autistic girls do not have sexual needs. Huda, a Saudi mother, expressed her happiness at having a boy with autism:

I am so happy I have a boy with autism and not a girl. Dealing with puberty would've been a nightmare. I know Ali might have reached puberty but I do not pay much attention to these things. I only fear sexual assault because Ali could be an easy target for others. As for masturbation there is no way my son would do that. (Huda, SA)

Sarah and Noha both believed that it had become easier to deal with their sons as they grew older. Yet Sarah expressed a worry about him ignoring people close to him such as his sister:

This really bothers me, because I want Maher to learn how to take care of people who would be his responsibility in the future. His sister complained about him ignoring her all the time. (Sarah, SA)

Since Amal is the only person who cares for Kareem, she feels tired most of the time: *'I feel exhausted mentally, physically, and physiologically all the time but I have no choice'.*

Rasha could not decide whether it got easier or harder: *'I cannot say if it is easier or harder, all I can say that I got used to his situation'.*

Rasha and Maha both feel confused and scared about adolescence. Rasha said:

Sami has reached puberty and I have no idea how to deal with him. As the days pass by, my fear grows stronger. (Rasha, SA)

Maha expressed similar feelings:

I really don't know what to do in order to help Amir during this stage. I feel helpless since I don't have the ability to help my son or make him feel better. (Maha, SA)

Rasha takes care of sensitive issues such as removing Sami's hair from sensitive areas. For reasons of cleanliness, in Muslim religious practice, pubic hair is shaved off the bodies of men and women: *'I feel shy and embarrassed but I have no other choice, I cannot just leave my son like that'*

Of course, adolescents with autism have sexual needs just like their peers who are not autistic. Yet, inappropriate sexual behaviour may occur due to their lack of understanding of the social norms which dictate acceptable behaviours within society (Beddows & Brooks, 2015). Rasha is not sure about Sami's sexual behaviour since he has not shown any though he once indicated his interest in the opposite sex when he printed a picture from the internet of a bride and a groom:

One time he printed a picture of a bride and groom and brought it to me. I do not know what goes on in his head when it comes to these things, and I do not know how to deal with him. (Rasha, SA)

Mai and Sana'a both hope their sons do not have sexual behaviour. Mai said:

Rami reached puberty, but he still hasn't shown interest in the opposite sex and hasn't displayed any sexual behaviour. To be honest, I would feel comfortable if he didn't show any of that. (Mai, SA)

Sana'a expressed similar feelings:

I hope he doesn't reach the stage of sexual desire, but if he does, I know it would be out of his control. I haven't talked to him to explain sexual behaviour and puberty. If he is not paying attention to these things, I don't want to open his eyes unless I have to. (Sana'a, B)

The sensitivity about sex is an issue of concern among many of the participants, the reality of which some would prefer to avoid. Yet studies show that when parents are involved in conversations about sex, puberty and sexual changes this has a positive influence on their behaviours (Ballan, 2012), as Sarah suggests:

I talked to Maher about the meaning of puberty, and I explained to him the changes his body will go through. I told him that this is normal and it happens to everyone. It was important for me that he did not feel shy because of these changes, and that it is normal and ok to have them. I also talked to Maher about autoeroticism, and he needs to take showers when it happens to him. He has erections, so I start buying him big underwear and I explained to him that he should wear wide boxers especially when he goes out because it is socially inappropriate. I also talked to him about marriage, and I told him the only person who is allowed to see him later on is his wife. (Sarah, SA)

Noha, Nada and Rana try to divert their sons' attention from sexual behaviour. Noha tries to interrupt him every time:

He started sleeping a lot on his tummy and moved differently. I often interrupted him by asking: Khalid what are you doing? So he stopped immediately. I was thinking of taking him to a psychiatrist to help him understand his new behaviour. (Noha, SA)

For Rana, although the changes that happened to her sons make things harder to handle, she feels good about it:

He is a teenager now. He wants to have an opinion and try new things. I believe this is his right. Just because he has autism doesn't mean he cannot have the desire to try new things or to act like a teen. It is good that he is trying to break the routine, to change is good ... although these behaviours are annoying, they make me happy. They mean my son is growing, and he is stepping out of his routine. He is willing to be moody and try new things. (Rana, SA)

In the next section I will discuss mothers' interpretations of their adolescents' behaviours.

Mothers' Interpretations of their Sons' Behaviours

Only two mothers in Saudi Arabia had their own interpretations of the changes happening to their sons, Nada and Sarah. Nada thought her son was being sexually assaulted by his nanny:

At first, I thought his nanny was doing something to him, so I installed cameras in the house without her knowing, but I found nothing. (Nada, SA)

Sarah does not expect her son to show any sexual interest: *'I do not really expect my son to be sexually active, because his father is cold.'*

The remaining Saudi and Bahraini mothers, did not have any interpretations in regard to this stage. Some like Mai (Saudi) and Sana'a (Bahrain) hoped their sons would not 'become' sexual beings. Next I will discuss mothers' behavioural response toward their adolescents.

Mothers' Behavioural Responses

Mothers reacted differently to the adolescent stage (see Table 5.12, Appendix Five). Some were keen to make their sons as independent as possible, while others still fully attended to all of their sons' needs. Support for this kind of care is, unsurprisingly, not usually available.

Eight mothers in both countries took care of their sons' basic needs such as hygiene, showers, brushing teeth and hair removal from sensitive areas.

Other mothers tried their best to avoid speaking about adolescence perhaps through fear of drawing their sons' attention to certain behaviours, especially sexual behaviour.

Sarah believes that giving Maher space and freedom is important for his upbringing:

I do not like forcing my children to do anything. We were forced into many things when we were little, and I want my children to enjoy their freedom. Yet the only issues we are facing now is that Maher plays video games for about 14 hours daily, and I just cannot stop him. He also spends a lot of time watching Japanese animations. He watched about 800 episodes in three weeks. I know I am weak with Maher and cannot stop him from doing what he wants; it is difficult for me to ban these cartoons or take them away. I feel his entire world would collapse if I did. (Sarah, SA)

Sarah also talks to her son about puberty and sex.

I talked to Maher about the meaning of puberty, and I explained to him the changes his body will go through. I told him that this is normal and it happens to everyone. It was important for me that he did not feel shy because of these changes, and that it is normal and ok to have them. I also talked to Maher about autoeroticism, and he needs to take showers when it happens to him. He has erections, so I start buying him big underwear and I explained to him that he should wear wide boxers especially when he goes out because it is socially inappropriate. I also talked to him about marriage, and I told him the only person who is allowed to see him later on is his wife. (Sarah, SA)

Noha, Nada, and Rana try to divert their sons' attention from sexual behaviour, with Noha saying:

He started sleeping a lot on his tummy and moved differently. I often interrupted him by asking: Khalid what are you doing? So he stopped immediately. I was thinking of taking him to a psychiatrist to help him understand his new behaviour. (Noha, SA)

Rana sometimes allows her sons to break the rules:

Other behaviours emerged such as refusing to eat on the kitchen table. Now he wants to take the food to his room and to eat in front of the laptop. Sometimes I allow him to do this, and sometimes not. (Rana, SA)

Noha and Asma'a taught their sons to be independent. Noha said:

I am trying to teach Khalid to be independent and to have opinions of his own. For example, when we go shopping, I ask him to choose his own clothes. (Noha, SA) Asma'a: 'He learned order, to clean his room, take care of his personal things'.

During this phase, and as noted above, many changes occur in the children's behaviours when they reach adolescence, and mothers reacted differently. While some mothers accepted the changes as a normal part of growth, others were uncomfortable and wished their sons would not feel or experience any sexual desires. Surely, living in a conservative society where discussing sex is a taboo, many may struggle with accepting sexual behaviour as normal, especially for adolescents with autism who, even though they have sexual needs, often find it hard to express them or to deal with them appropriately as noted by Cheausuwantavee (2002).

5.3 Summary

In this chapter I have presented a thematic analysis of the mothers' experiences with autism across the three phases of pre-diagnosis, diagnosis and post-diagnosis. In addition to the themes that emerged from the data, I discussed in detail the mothers' responses according to the broad themes and the sub-themes. I gave examples by quoting from the mothers' conversations to illustrate their views using their own words in order to have their voice heard. I noted ways in which the mothers' responses often pointed to an implicit, a tacit medical model of disability in which autism was viewed as a problem requiring medical care and treatment and that autism was possibly explained by medical causes. Importantly, many of the extracts in this Chapter suggest that the mothers in the study regarded their sons' autism as a problem and they pointed to it, if I re-frame that in the social model, as 'synonymous with oppression or disadvantage imposed by society' (Barry, 2012, p.3). Their responses in the next Chapter amplify this.

On each day of their journeys with autism, many of the participants felt overwhelmed with feelings of stress and isolation. They expressed feelings of helplessness and loneliness, questioned their ability to care for and help their sons, and learned to expect and manage

day-to-day challenges often on their own. Such feelings, especially with a lack of support could have a significant effect on the mothers' own wellbeing. In the next chapter, I will discuss mothers' experience with respect to social support, both formal and informal, and I return to the diagnosis phase if the mothers talked of, for example the support, or lack of support, offered by their spouses during this phase.

Chapter Six: Social Support - A Thematic Analysis

On our own we simply don't know how to get things done the same way you do things. But, like everyone else, we want to do the best we possibly can. When we sense you've given up on us, it makes us feel miserable. So please keep helping us, through to the end.

Naoki Higashida, 2013, p.40

6.1 Introduction to Social Support as a Broad Theme in Saudi Arabia and Bahrain

Naoki, a 13 year old, non-verbal boy with autism who provides the epigraph above, shares his thoughts, ideas and feelings in a powerful way. Naoki urges the world not to give up on individuals like him, expressing feelings of misery at not being understood and for making others feeling awkward in their company. These are similar to the feelings I believe mothers in my study experienced because of lack of help and support, and their awareness that others may not understand their sons. As the mothers have recounted in their journeys, they know that their sons 'don't know how to get things done the same way' that other children and young people do. They, like Naoki, want others to help them through to the end. In this chapter, I will present mothers' stories focussed on social support in both Saudi Arabia and Bahrain and do so through data, through their voices, with respect to both informal and formal support.

If I apply the social model of disability here then it becomes clear that, in both Bahrain and Saudi but perhaps especially in Saudi, support, both informal and formal, rarely reflected attitudes that the social model would promote. In the last Chapter, I pointed to attitudes suggesting autism was a problem for the individual and, indeed, for his carers, here the mothers. While there was evidence in that last Chapter of autism as disability being 'synonymous with oppression or disadvantage imposed by society' (Barry, 2012, p.3), further evidence of this comes out in the data in this Chapter. Oliver's (1990) view that it is society that is the disabler as much if not more than impairments and his claim that society makes impairments worse by isolating and excluding individuals, thereby making it impossible for them to fully participate in society (Oliver, 1990) becomes evident here. As noted throughout, the extent to which mothers of adolescents with autism can access social support is a key research question, and is central to the development of the capabilities of the mothers and their sons, an argument I shall develop with particular

respect to the mothers in this study in the next chapter. During the interviews, I discussed the kind and quality of spousal and family support that the mothers and their adolescents received. I refer to this kind of support as ‘informal support’. I also explored the kinds and quality of formal social support received from schools, Ministries and hospitals, both negative and positive. The sources of support received are summarised in Table 6.1 below. I also discuss mothers’ affective and behavioural responses. As I will argue in this chapter, receiving appropriate support helps parents deal with, and understand, autism, and enhance the quality of their affective lives (Cortez et al., 2011). As I have already stated, Autism Spectrum Disorder (ASD) can put enormous stress on parents in general, and mothers in particular, as they are often, and in this study always were, the primary care takers (Cantu, 2010). As I discussed in Chapter Two, in a country like Saudi Arabia which is governed by restrictive rules and regulations, my data clearly indicates the difficulty mothers have trying to acquire the support they need with the result that they often feel stressed, isolated, lonely, and fearful.

Table 6.1 Social Support as a Broad Theme

	SOCIAL SUPPORT							
INFORMAL	SOURCES OF SUPPORT							
Behaviours (including their attitudes)	Spouse		Family and friends					
	Pos	Neg	Pos			Neg		
Mothers’ responses	Affective		Affective					
	Behavioural		Behavioural					
FORMAL	SOURCES OF SUPPORT							
Behaviours (including their attitudes)	Hospital		Autism centres- schools		Other (governmental, leisure facilities)		Society	
	Pos	Neg	Pos	Neg	Pos	Neg	Pos	Neg

Key

Pos= Positive

Neg= Negative

6.2 Social Support - Informal social support

Spouse Support

In general, husbands in Saudi Arabia play a different role in the lives of their children in comparison to husbands in Bahrain. Because of the male guardianship law (described in Chapter Two), which places a woman under the control of her male guardian, a woman is not allowed, for example, to enrol her children in schools or apply for a disability card without the written permission of the child's father. In Bahrain this law does not exist so a Bahraini woman can move about freely, while a Saudi woman is dependent on a male driver, usually her husband. Lack of mobility impacts greatly on mothers' ability to obtain support, as I will show below. However, mothers in both countries said they experienced negative support from husbands, although the Saudi mothers in my study experienced more difficulties than did the mothers in Bahrain (see Table 6.2, Appendix Five for summaries of the negative forms of support that mothers in both countries received from their husbands). The lack or the absence of the spouse's support is an important contributor to mothers' level of stress (Meadan et al., 2010), and support, as Asma' explains, is crucial: *The most important support anyone can find is within the family. I think the family makes a difference in the mother's ability to handle and deal with her son's disability. I am grateful I have a supportive family who helped me through this. (Asma'a, B)*

As Asma'a unequivocally states here, positive spousal and familial support can make a powerful difference to a mother's quality of life and on her ability to support and nurture her own child. I will discuss such issues later in the chapter.

Nine mothers in Saudi and two in Bahrain reported that they lacked support from their spouses. Their spouses were close-minded, traditional and controlling. Rana's husband, example, will not allow her to speak to men, not even about her own son.

My husband doesn't allow me to speak with men, which is why I cannot call the teacher and ask him about my son. Only if I know for sure that the teachers won't tell my husband, will I call. (Rana, SA)

Fatima had to live with a controlling husband before she was divorced. Not only had she no support from her husband, but was also prohibited from attending hospital. Though she had no control over this, it was she who was judged as a negligent parent, not her husband: *People used to blame me for not taking my children to the hospitals. They thought I was a careless mother but their father did not allow us to go. (Fatima, SA)*

Rana struggled with her husband's close-mindedness, describing her husband's attitude in detail about her getting a job in another city, their sons' future, and even about having another wife. Living in a patriarchal society that prefers sons to daughters, and which follows a strict division of labour, women are entirely responsible for the household, as I explained in Chapter Two. This detailed account from Rana, sadly, describes the fate of far too many women:

As for Yazeed's future, my husband said to me, "In a year or so I want to find a bride for Yazeed". I was shocked and asked him "How and why are you planning to do that?" He said he could have a son to take care of him! Then I asked him how Yazeed was going to sleep with his wife. He said he will learn this on his own; no one needs to teach him. One of the reasons my husband wants to marry off Yazeed is so he can get a grandson. He says to me, "Let him get married and have a son, isn't it enough that I cannot have a normal boy?" "What if he has a son with autism", I argue. He said, "Not necessarily". "Yeah but you never know", I reply. Then I asked "Who is going to marry your son anyway?" "We can travel abroad and get him a girl from another country, to give us the son we need. Then she can leave if she wants", he said. I replied with silence. My husband always says things like: "I want a normal son", "I want a son I can depend on", and so on. Yet, he said he doesn't blame me or blame himself. He said he knows we cannot control this. My husband is a very close-minded man. Since I married him, he hasn't changed. On the contrary, he is getting worse. When I got pregnant with my first child, and we found out it was a girl, he was very annoyed! I will never forget what he told me when we were still engaged "I never want to have girls, I want all my children to be boys!" Whenever I look at my children today I remember his sentence, and how we end up with typical girls and autistic boys! When I got pregnant the second time and we found out it was a boy, he was over the moon. This is why it is hard for me to blame him for his actions sometimes. My shock is nothing compared to his. Also, he always nags about having the boy; he even said he wants to marry another woman just to have a boy. I told him "It is your right, but if you do I want a divorce". He said he wants a boy to carry his burden when he grows older. He said "What if something happened to my daughters? Who is going to take care of them? They need a brother". (Rana, SA)

Rana's circumstances are challenging. She is a mother of two boys with autism, and has an unsupportive husband. She experiences, in my terms, negative support and yet she is forgiving: 'it is hard for me to blame him for his actions sometimes' and seems almost to excuse his lack of support when she says: 'My shock is nothing compared to his'. Such

behaviour indicates adaptive preferences when a mother is made to accept her situation in preference to another, especially if she does not have the ability to change it (see Chapter Seven). Rana's forgiving nature and her rationalising of her husband's behaviour can also be explained by the internalisation of beliefs about women's naturally caring natures and roles as mothers. As I argued in the Chapter One, families are where we first learn our values, morals, and beliefs about who and what we are. The family is also, of course, where we internalise the norms about gender hierarchies (Moller-Okin, 1989). Rana's husband is 'over the moon' when he learns he is having a son but is later disappointed when he learns that he too is autistic. However, Rana cannot 'blame him for his actions sometimes' because this is how many Saudi men (and women) are brought up – to believe that girls are less valuable than boys.

Another mother who experienced similar lack of support from her husband and her family is Nada, but for different reasons. When Nada received a scholarship to study in the USA, it was she, not her husband, who received the brunt of criticism for wanting to expand her horizons:

I faced a big problem with everyone before leaving for the States. Everyone ... attacked me: how am I going to manage on my own? And why do I want to break my family? Even though my husband supported this move entirely, he was affected by his family's opinion, the customs and traditions. For example, he would call me while we were in the States and ask me to bring the boys back. ... I am the one who supported myself, and gave myself the power to continue. Not even my husband was there for me. (Nada, SA)

While Fatima had no control over whether to take her son to hospital, and Rana had to contend with her husband's fury at her taking a job in a different city, Nada, a talented woman, likewise faced the disapproval of her family merely for wanting to further her education. As for Nora, she has an abusive husband who used the male guardianship law to his advantage, even to the detriment of his own daughters, the eldest of whom he did not allow to attend university until his youngest daughter was able to attend with her, a wait of two years. The other difficulties Nora had was that she could not enrol Ahmed in school unless her husband accompanied her and neither could she claim disability benefits from the Ministry of Social Affairs, as she reports here:

The first school I managed to contact rejected him [her son] without the presence of his male guardian, in this case his father. My husband refused to accompany me to the school.

I cannot even get my son's benefits. After getting Ahmad's evaluation report, I went to the finance department in the Ministry of Social Affairs and asked for the monthly allowance. They asked me if I was divorced. When I said "no", they asked my husband to come because they cannot give me the money. What can a woman do in this country? They said the male guardian has to come himself to take the money. (Nora, SA)

It is fair to say that such an attitude infantilises women. They are not competent enough to represent themselves or their children, or, presumably, to manage the money, despite the fact that women run the household. Having money, of course, means power and independence, forms of self-authority that can only be granted by the husband (or father). Nora's question 'what can a woman do in this country' is, of course, rhetorical though the answer seems to be a compelling 'nothing!', at least not without the permission of her guardian. The prohibition on driving allied with an unsupportive husband means that some mothers are powerless to do much to support their sons as Nora's story further illustrates. *My husband did not help me to enrol Ahmad in school. He does not help by driving us there. He acts like we do not exist. When I finally found a disability centre where Ahmad could attend I had no one to drive me. I asked my husband for help, but he told me to handle it myself. (Nora, SA)*

So, in this example, not only did Nora's husband not support her but he was actively obstructive.

While the issues of male guardianship and mobility are not issues that Bahraini mothers in this study had to surmount, a lack of financial support was a problem for some mothers in Bahrain (as indeed they were in Saudi) as Maha says:

My ex-husband sends me legal benefits for divorced women, yet this money is nothing when compared to Amir's needs. Autism is an expensive disorder, and my son is in a boarding school in Jordan. (Maha, B)

Getting children accurately diagnosed with autism can be stressful and time consuming as my data suggested in the last chapter and, at this time, the data from this study confirms that support is crucial. However, as many of the mothers testified, they received little support, patience or understanding from their families, especially their husbands, some of whom were in angry denial. Mai, (a Jordanian living in Saudi), describes her experience: *I tried seeking different opinions when my son was first misdiagnosed with his intellectual disability. Yet, my husband did not support me. He refused to go to any more doctors; he*

was impatient and short tempered. It was hard for me to do anything on my own. When I used to ask him to take us to the hospital, he would tell me the topic was closed, “Rami is already diagnosed, why do you want to waste our time moving between doctors?” (Mai, SA)

Maha’s problems were similar to Mai’s:

My husband, his family, and even my family kept saying that Amir is fine and that I was worrying for nothing and imagining things. We stayed like this until Amir reached four years old when I managed to get him diagnosed. (Maha, B)

Rana again suffered from her husband’s angry refusal to accept the inevitable, insisting that his son had been affected by some evil spirit especially when Yazeed screamed and cried when he was touched by the Imam. When the Imam’s intervention failed, her husband turned to herbs and honey:

My husband was furious when I first mentioned autism ... he insisted that his son had the evil-eye and started jumping from one ‘Imam’ to another to read the Quran to Yazeed ... he was convinced that someone had cast an evil spell on Yazeed, especially because he would cry and scream when the ‘Imam’ put his hand on his head and read the Quran. ... Then, he started trying honey and all sorts of herbs. I kept telling my husband that Yazeed has autism and whatever he is going to do won’t change this fact; he would then shout at me and call me crazy. (Rana, SA)

As noted in the previous chapter, a couple of mothers, Warda and Rasha, also thought that some evil spirit possessed their sons, while Fatima resorted to prayer.

An additional reason for the mothers’ levels of stress and sense of powerlessness came from their husbands’ refusal to take part in their sons’ education. This is from Amal:

My husband rarely visits Kareem’s school to check on his progress. When they have parents’ meetings in Kareem’s school, his father sometimes goes. Even though he is retired, he says to me ‘You are the mother, Kareem is your responsibility, and I am busy’ (Amal, SA)

Despite the fact that Saudi women cannot normally enter their sons’ schools and that some schools will insist on contact from the father first, the mothers are still expected to assume full responsibility for their son’s care as Mai notes below:

Rami’s father was not supportive at all. He did not absorb Rami’s condition. Even when Rami was in the centre, if anything happened they’d call me and not his father. When Rami

moved to the male department, nothing changed, they were still in contact with me.

Sometimes, I had to go meet the teacher in person. If necessary, we were allowed to enter the male centre but only if the students were not present. (Mai, SA)

Nada tried to be sympathetic to her husband: I always push Adel's father to go to his school to check on him. I know he cares but, like most men, he needs to be pushed sometimes. (Nada, SA)

To accept, understand and live with their husbands' indifference, disinterest or simple lack of support, Nada excused her husband's behaviour on the grounds that he is just like all men, as I will discuss in the next section on mothers' affective responses.

The complex and bewildering behaviours of autism, along with angry denial, if not ignorance of the condition, meant that the mothers' had also to contend with blame and poor care. The husbands of Rana and Amal (Saudi), and Maha (Bahraini), blamed their wives for their children's autism, as Amal, for example, describes when they got the diagnosis:

... it made no difference to Kareem's father. He knew Kareem had a problem, but knowing the problem's name did not change anything. Also, instead of helping me he always blamed me and accused me of spoiling Kareem. (Amal, SA)

As for Maha, her relationship with her husband became distant and lead to separation:

He started blaming me for Amir's condition as if I am the one who caused him the autism. He never accepted Amir and if the father is not convinced with what God has chosen for us then there is no point. It became so hard we ended up having a divorce. (Maha, B)

Sarah (Saudi) and Warda (Bahraini) had to live with their husbands' impatience with and shame occasioned by their sons. The women learned avoidance tactics, minimising the time their husbands spent in their sons' company in order to prevent further anger or violence as Sarah illustrates:

Maher's father just cannot handle his behaviour. For example, Maher did not learn how to eat properly until he was about 10 years' old. We were on a family holiday in the States, and his father always lost his temper when we went out for food because of the way Maher ate and drank. When we are in Saudi Arabia he does not see Maher much - we have our lunch when his father is at work, so he is not used to Maher's ways. (Sarah, SA)

Warda, too, had to learn avoidance tactics, often taking the blows he tried to mete out to this father:

When Taher had tantrums either because of his migraines or because something annoyed him, his father didn't know how to handle him. I usually stand in the middle and tell him to protect himself because I could tell from Taher's eyes where he was going to hit him, and I ended up taking the blows myself. (Warda, B)

Being autistic, as I explained in Chapter Two, and as the data showed in Chapter Five, is not easy on the parents. Warda, in this case, realised the difficulties her son was facing and she managed to develop an understanding for his situation to the extent that only by looking at his eyes could she predict his behaviour. Warda was also the buffer between Taher and his father to protect her son and keep the peace in the house. Many fathers withdrew from their sons' lives as a coping mechanism to a condition they did not understand or want to acknowledge as Rasha describes:

I am fully responsible for Sami. I have to remove hair from his sensitive areas. I asked Sami's father for help, but he refused. I felt shy and embarrassed but I had no other choice. (Rasha, SA)

It is Rasha, not her husband, who has to deal with the embarrassment of taking care of young man's personal care. Rana talked about the same issue:

Unlike my husband who chose to run away and separate himself from us, I did completely the opposite. I stopped going out, stayed away from everyone including relatives and friends. I decided to dedicate myself completely to my boys. (Rana, SA)

Nora's situation is complicated further by her unfaithful husband whose contact she cannot now endure (but she must, as his wife). His lack of support for any aspect of his family's care and well-being, even her bodily integrity, has impacted on her health. When she told her husband that their driver had sexually and verbally assaulted her, he advised her to ignore it and keep the girls at home (they were attending university):

I am diabetic, and have high blood pressure and I do not want to lose my health because of him. He is not a good father and my children need me. He does not care about us. (Nora, SA) Five spouses in Bahrain and two in Saudi Arabia, however, reacted positively towards their wives and their sons' conditions (as summarised in Table 6.3, Appendix Five). They were helpful, interested and willing to talk about how to plan for their sons' care. Noha, for example, told me about how she and her husband decided to send Khalid to Egypt:

One day, one of my husband's friends told him about his cousin who also has autism, and how his parents took him to a boarding school in Egypt. My husband came home and talked to me about it, and I thought this could be a good idea. Khalid was about five years old when my husband and I discussed the idea of sending him abroad. Then we both travelled to Egypt first to check the school before we enrolled Khalid. We liked it a lot, and we decided to send him. (Noha, SA)

Samia (Bahraini), shared the same experience, saying of her husband: 'He supported my decisions when it came to the children, and he helps me a lot in choosing what is best for them'.

Noor, a Bahraini mother, reported her husband's care for her comfort:

During the first week of Waleed's going to the psychiatrist, my husband came back to stay with us for three days before his second mission [he is an army doctor]. During this time, I saw him reading and researching a lot and I didn't know what he was doing. During that time and before the diagnosis, my husband knew that Waleed had autism but he didn't say anything to me. I called him after receiving Waleed's results and I told him what they said. He replied that he had known all along but didn't want to upset me since the hospital would inform me anyway. My husband's job doesn't allow him to be around much, but whenever he sees me tired he asks me to take a break, to leave Waleed with my family and travel somewhere to relax and rest. (Noor, B)

Nouf, Samia, Noor and Asma'a (Bahraini) are all supported by their husbands. Here, for example, is Asma'a's account:

My husband was very supportive and cooperative; he helped me a lot. He was one of the reasons we managed to get Khan's diagnosed that quick. He went with me to the doctors; travelled with us to Kuwait; and did everything in his power to figure out what was happening with Khan. He didn't leave my sight. (Asma'a, B). Samia also said: 'My husband was my pillar during this long journey. There are so many things I could've not done without him'.

Unlike the fathers I discussed earlier, Nouf's husband does take responsibility for their son's personal care:

Sultan doesn't know how to remove the hair from his sensitive areas. His father is dealing with this. He goes to the toilet with him and uses the hair removal cream. (Nouf, B)

Nouf expressed her comfort when she was talking about her husband and how he fulfils his responsibilities towards their son, particularly when it concerns things the father usually does and I will now discuss mothers' affective response toward their spouses' behaviours.

Mothers' Affective Responses

Mothers in both countries experienced different emotions such as blame, loneliness, and depression about their spouses' behaviour towards them and their sons, and their lack of support (see Table 6.4, Appendix Five).

Asma'a, a (Bahraini), expressed positive feelings:

The most important support anyone can find is within the family. I think the family makes a difference in the mother's ability to handle and deal with her son's disability. I am grateful I have a supportive family who helped me through this. (Asma'a, B)

However, Huda, Amal, Rasha and Nora (Saudi), all described feelings of loneliness. As Amal said:

It has been, and still is, a lonely journey where it is just me and Kareem. Whenever his father helps us, he made us feel like he is doing us a favour. Like we did not deserve help or support, and he is doing charity. (Amal, SA)

Rasha felt the same feelings as Amal:

I have no help or support. The only person who truly cares about Sami is me. As long as I breathe and have the ability to move I will keep taking care of my son, and fulfil all his needs. (Rasha, SA)

Mai (Saudi) used the word 'depression' to describe her feelings: *'I feel depressed. Without a supportive husband, things become unbearable'.*

Sarah started doubting herself:

I was always home with Maher and my husband. Since their behaviours are similar, I thought I am the weird one. When I started to leave the house after getting my job I realised that my behaviour is normal and Maher and my husband are different. (Sarah, SA)

Maha found strength after her divorce:

I read that 80% of mothers who have children with autism end up with a divorce which I believe is true. After the divorce, I decided to be Amir's mother and father; and I asked God for strength to take care of my son without needing anyone. (Maha, B)

Now I will discuss mothers' behavioural response toward their spouses' behaviour.

Mothers' Behavioural Responses

The mothers, as we might expect, reacted differently toward their spouses' behaviour.

Some resorted to prayer, others tried to find excuses for their husbands (see Tabel 6.5, Appendix Five).

Maha, for example, tried her best not to make her son feel unwanted by his father:

Amir's father would visit him in Jordan only once or twice a year. Although he is not involved in his life, I try my best not to let Amir feel unwanted. When I go visit Amir in Jordan, I send a text to his father asking him to call Amir and pretend he did it on his own, so Amir feels that his father is present in his life and that he cares. Just because his father and I aren't together anymore, doesn't mean that Amir has to suffer. I don't want him to grow up thinking he doesn't have a father. (Maha, B)

Amal (Saudi) shared her opinion of her husband's behaviour:

I do not usually blame my husband for his dereliction because I know nothing will change him. He will be the same lazy, careless, neglectful man. You know how they say disasters change you? We had our disaster, I do not think there is a bigger disaster than losing your son. If this did not change him, nothing will. My husband is a man with no interest, no hobbies, he stays home all day long watches TV, drinks his coffee and goes to bed early. I feel he is also in need, he is anti-social, has no friends, he does not even care about other women. It is hard to trust my husband to stay with Kareem or take care of him. When I was in the UK for my studies, I brought a helper with me from Saudi Arabia to take care of the house and Kareem. And one day I had to go to the university for registration, and I left Kareem at home with the helper and his father. The helper told my husband that she is taking Kareem to the park, he let them go alone, and he went somewhere else. Then the helper ran away and left my son alone in the park, he was young back then. We had to call the police to search for Kareem. (Amal, SA)

Family and Friends' Support

Informal support from family and friends is associated with reducing stress levels among parents (Hastings & Johnson, 2001) because, according to Bashir et al. (2014), family support helps parents of children with autism overcome the challenges of caring so alleviating the stress they feel. Informal support comes from family members, friends, and in some cases neighbours, helpers and drivers. Just as the support of the mothers' husbands varies, so does the support of family and friends (see Table 6.6, Appendix Five)

Family support varies from acceptance or financial and physical support. Two Saudi mothers, Fatima and Nora, were supported financially by their families, as Fatima explains: *I am an orphan, so I don't really have any family. Yet, I have two aunts and they help me with money from time to time. (Fatima, SA)*

As for their other children, most families were supportive and helpful towards their brothers with autism. Nora said:

My other children try their best to help me. They even give me some of their pocket money to help with Ahmad. (Nora, SA)

Sarah, another Saudi mother, describes how her daughter has helped her since she was a little girl:

... she taught Maher how to eat on his own. I always give him instructions on how to eat properly but he would often not listen. His sister ... followed a completely different approach. She would eat with him and say: "See? This is how we should eat". So he would imitate her. Yet such support became less when both brother and sister reach adolescence. (Sarah, SA)

Many Bahraini mothers have the same positive experiences with their other children, as Noor explains: *My son has been really helpful. Just like my daughter, they both help with their brother in any way they can. (Noor, B)*

Warda, has similar experiences:

The reason we thought of having another boy was to get Taher a brother for support. I was worried at the beginning about getting pregnant again in case I had another child with autism. Then I thought I would take my chances - whatever God gives me I will be happy. My youngest even though 9 years younger than Taher, he loves his brother and helps him as much as he can. (Warda, B)

However, not all mothers received this kind of support. Amal (Saudi) described how Kareem's younger brother was too embarrassed by his brother's behaviour to get involved:

Kareem's younger brother was not supportive. He was very embarrassed by his older brother's behaviour ... He sometimes screams in public places, throws food or has tantrums. It was too embarrassing for his brother so he stopped going out with us. He often says to me: "People look at us, they laugh at us because of Kareem". (Amal, SA)

In the extract above the 'norm' as it is perceived by others and a deficit attitude towards Kareem is clear. His brother is apparently focussed on what is different about Kareem and, inevitably, the reactions of others to Kareem's behaviours reflect the sort of discrimination caused by cultural attitudes, as noted by Terzi (2004, and referred to in Chapter Three). I have noted that the social model of disability holds that society discriminates against individuals with disability and, going beyond that model, Nussbaum's Capability Approach (2009) argues that people with cognitive disabilities should be treated as equal citizens. Kareem and his carers, here his mother, seem very far from 'equal citizens'. Indeed, comparable examples here illustrate that neither the social model of disability with its call for society, not those with impairments, to change or the Capabilities Approach are yet informing care and support for the autistic adolescents in this study.

Families can be divided by the complex needs of a sibling and child because so much attention must be given to that child, often at the expense of other children and/or the husband. Mothers have to contend with sibling jealousy (Raha), resentment (Rasha) or sacrificing other children's happiness (Warda, Nouf and Rasha) because they lack good support. Amal actually lost her younger son in a car accident a few months before our conversation took place and felt his accident might have been brought about by his despair at feeling neglected for his brother's sake:

Kareem became closer to me since he felt I was the only one protecting and understanding him. And the closer he became to me, the further apart he became from his father and brother. Perhaps Kareem's situation is what caused my younger son's despair. How our family is divided and separated is perhaps what caused his pain and lack of attention, the lack of attention which might have caused his car accident. (Amal, SA)

Rasha (Saudi) also had little support from her other children:

My older son is just like my husband; he does not care. On the contrary, he says to me, "mom you are wasting your time with Sami, you are working hard for no reason. Sami will not improve, and you should consider putting him in a disability home". I tell him "this is your brother, how can we abandon him like this? Your brother cannot even speak. If

someone hurts him he won't be able to complain". No one cares. Only one of my sons, the one in high school, he is the only one who helps me with Sami. He takes him out, plays with him and buys him stuff. Also, one of my daughters helps me with her brother but she got married and left home. (Rasha, SA)

Huda was avoided by her extended family and the stigma associated with autism, and lack of understanding of the condition, meant that her girls were not marriageable. Once again, there is a sense of being blamed for the child's autism and of society isolating autistic individuals and, in turn, their carers:

Our extended family is avoiding my daughters. They fear that autism is hereditary so no one will propose to them although my daughters are the best in the family, they are the only educated ones. Also, my older sister has some mental problems, and I can sometimes see it in my husband's eyes that I am the reason why Ali has autism. (Huda, SA)

Warda (Bahraini) is also struggling:

Taher is the centre of my attention. I couldn't help but care for him more than my other children. My oldest daughter feels jealous when I go visit Taher in Jordan. I tell her, "I am with you for the rest of the year, but I only visit Taher for a couple of weeks". I tell her she cannot compare, she lives with me, he doesn't. I say to my daughter that I sacrificed and sent Taher to Jordan so she can study and her little brother can be safe and her father can work. Yes, I am devoted to Taher but they are different. I also told her that Taher needs me more than them, at least they can talk and ask for their rights but he cannot. So I always tell her not to break me, be successful and have a bright future. (Warda, B)

On the other hand, many mothers, such as Samia and Noor, have supportive families:

My sister is the one who was always there for me. She used to live in the States, she was far from me yet she was always calling and talking to me. (Samia, B)

Noor is another example:

I consider myself very lucky for having so much support around me; I was never alone during my journey with Waleed. Everyone around me did everything they could to help. I was that blessed. (Noor, B)

Nora had some supportive and helpful neighbours:

I will never forget my neighbour's help. She is the reason, after God, to guide me what to do with Ahmad and how to help him. She is the one who found the first disability centre to take the kids and she would even pay for the driver and refuse to take the money from me.

(Nora, SA)

Sarah had the support of both a nanny and a driver who helped her overcome her sense of depression:

The nanny I have at home tells me that Maher is intelligent and different from other kids in a good way. Whenever I feel depressed because of Maher's condition, she reminds me that Maher is a good boy and that his differences are actually positive. Also, Maher has a good relation with the driver. He talks to him a lot. Maher even learned a few Hindi words from the driver and was able to form complete sentences. The driver also taught Maher the meaning of jokes, since Maher tends to understand everything literally. But by talking and laughing with the driver he understands what it means to be funny and tell a joke.

(Sarah, SA)

In the extracts above it is clear that whatever the support the mothers receive, whether positive or negative, it has, inevitably an affective dimension. Good support resulted in gratitude, prevented loneliness and created a sense of belonging and worth. Lack of good support meant that many, if not all mothers, worried about the future and the well-being of their sons, as I will now discuss.

Mothers' Affective Responses

Most mothers were worried about their sons, especially when they did not have supportive family members. Even when they do have support, they still believe no one will care for their sons like they do. Mothers all expressed concerns about their sons' futures with little hope that society might change to include and care for their sons as the social model of disability would recommend. This, for example, is how Huda described her concerns for Ali:

I worry about Ali all the time. I know no one will take care of him if something happens to me or to my husband. I have an older sister with mental problems, after my mother passed away there was no one left to help her. Even I got busy with my family.

Nora described herself as an orphan:

I am an orphan, both my parents are dead and I have no one to help me with Ahmad not now, not if something happens to me. My mother passed away when my oldest daughter was about one year old. My other sister died of breast cancer, and the other one died with kidney failure. My father died five years ago. I am left with no one. Both my brothers live far from me and are busy with their lives. I am all alone. (Nora, SA)

With no family to support her, Nora really does feel alone and her son's future without her is not certain. Bahraini mothers reported similar fears as Nouf described:

Ages ago, when my children were younger they asked me a question, "Mom when you and our father die who is going to take care of Sultan?" We will all get married and Sultan will have no one with him". I replied saying that "God will take care of Sultan, and he will provide him with people who will love him and care for him. I know they didn't mean anything by asking and they were very young, but it was a good question which I can never forget. Who is going to take care of my son if something happens to me or my husband? (Nouf, B)

Many mothers either appealed to their other children for help or resigned themselves to managing without help, as I will now discuss with respect to mothers' behavioural responses toward their families' and friends' support.

Mothers' Behavioural Responses

Mothers acted differently towards their family and friends. Fatima tried talking to her older, 'careless' son:

I tried talking to my older son several times about his behaviour and how is he supposed to be an example for his younger siblings, especially because their father is not in the picture. (Fatima, SA)

Like Fatima, all Rasha could do was talk to her other children:

I always encourage my other children to be close to Sami, feel compassionate about him. I always say to them that this is your brother, he did not chose to be this way; this is his destiny. (Rasha, SA)

Asma'a, on the other hand, was not ready to get anyone involved in her son's life:

The only issue with the family was that they wanted to be more involved in Khan's life, as in wanting to know more information about him, wanting us to be more in contact. At times

this was difficult since we were busy trying to understand what was happening with our son. (Asma'a, B)

Samia, with two children with disabilities, trained her nannies to take care of her children: *When the nannies arrived I sent them to the Autism Centre where they got training for three months, along with the training I provide for them at home. When you have children with disabilities you move in a vicious circle: you are always looking for someone who has the patience and the ability to provide care. (Samia, B)*

Children with disabilities require lots of attention and care. In Samia's case, who has a daughter with severe intellectual disabilities and a son with autism, both adolescents, taking care of them requires effort and time. In such cases, the financial situation makes a significant difference to the mother's quality of life, Samia has the financial resources to hire nannies and train them to help take care of her children, resources some of my participants did not have. For example, Fatima a single mother, who has three children with disabilities, takes care of them without any help because of her poor financial situation.

In summary, the support mothers receive from families or close family associates varies from the very supportive to practically no support. Having explored familial support with the mothers, I then asked them about their experiences with formal support, such as the services provided by the medical profession, Autism Centres or government departments. Starting with hospital support, I will now discuss this aspect of support.

6.3 Social Support - Formal Social Support

Hospital support

In seeking help for their adolescents with autism, all the mothers had to deal with hospitals and faced many difficulties in doing so (see Table 6.7, Appendix Five). In Hoefman et al's (2014) study of 224 parents of children with autism in the US, support had a positive effect on parents by improving their quality of life, effects which were confirmed by the mothers in this study (see above). In addition, medical and educational staff who understand parents' needs are better able to provide adequate support which improves the functioning of the family and reduces their levels of stress (Deris et al., 2012). Unfortunately, in this study, most of the mothers' experiences were negative as I indicate below.

As already noted in the previous Chapter, three mothers, two from Saudi and one from Bahrain, were not given information at the time of the diagnoses or much support in dealing with the condition. Talking of the social model, Oliver (1990) notes that numerous disabled individuals will experience medical intervention ‘as, at best, inappropriate, and, at worst, oppression’ and this is evident in some of my data. Following Oliver, rather than blaming the medical profession, it may be more important to realise that medics might be ‘trapped in a set of social relations with which they are not trained or equipped to deal’. This is because they are, of course, ‘socialised by their own training into believing that they are ‘experts’ and accorded that role by society’ and ‘they cannot admit that they don’t know what to do’.

Fatima, who cannot read or write, was given no advice from the hospital apart from being advised to ‘*make him play more with children his age and take him to a disability school and may Allah help you.*’ and Nouf, as I noted in the last Chapter, felt lost and bewildered. In two cases in Saudi, (Huda and Sarah), Sarah obtained a diagnosis from Autism Centre rather than hospital although she was asked to obtain an official report from the hospital. So, too, some hospitals in both Saudi and Bahrain failed to give correct diagnoses to some of the mothers, with Rasha explaining:

When Sami started acting in a weird way, I took him to many doctors. I explained to them his symptoms, yet no one said anything about autism. No one knew what the problem was. When Sami turned four years old, I took him to one of the doctors who applied an IQ test, and then said to me, “your son is foolish” (Rasha, SA)

Nada, shares a similar experience:

After noticing Adel’s behaviour, I started taking him to many doctors but none of them was helpful. They would tell me that all Adel needs is to socialise with others, take him to school, or make him play with children his age; they would say it is too early for any diagnosis. It was not until Adel was four years old when one of my friends recommended a well-known hospital in Jeddah and I took my son to the paediatrician there and finally received the diagnosis. Even though I had an earlier report only few months back saying Adel has no problem but a language delay. (Nada, SA)

In Bahrain, because of a repeated failure to recognise Saleem's autism, Sana's diagnosed him herself but this, she felt, had negative consequences:

Because of the doctor Saleem lost precious years of early intervention which makes me really upset. So I just ended up diagnosing my own son. To be honest, mothers diagnose their children better than the doctors do. I used to take Saleem to the regular check- up for the vaccine, which is mandatory, but none of the doctors noticed anything wrong with my son. I discovered at that time that our doctors are completely ignorant in regard to autism. They were useless, and whenever I am asked who diagnosed my son I said I did. (Sana 'a, B)

Nouf was in tears when she shared her experience. One doctor described her as 'delusional':

Whenever I visit a doctor they check Sultan then tell me I am delusional and my son is fine. I tried to convince them that I am not imagining things, and I am the one living with Sultan not them. I went to a psychiatrist as well but again he couldn't diagnose my son. I was sure there was something wrong with my son. (Nouf, B)

When the hospitals failed the mothers, some sought help elsewhere in countries like the UK, Jordan and Kuwait. Amal (Saudi) received her son's diagnose in the UK while she was studying for her PhD. Maha's (Bahrain) son was diagnosed in Jordan and Warda (Bahrain) travelled to Kuwait. Warda could not find qualified doctors in Bahrain:

One time, I remember it was 3am when I called the airport and managed to get a ticket at 7am to fly back to Jordan. It was during the holidays so I couldn't find any qualified neurologists in Bahrain. I thought about going to Saudi Arabia, but my husband wasn't around at that time and of course I couldn't drive there. (Warda, B)

Maha went abroad to seek medical help:

We managed to take Amir to Italy for his epilepsy seizures. They found out that the seizures focus⁸⁹ are all over his brain, therefore they couldn't operate to remove the infected area. The only treatment in his case would be medication. After our first trip to Italy, Amir was fine for about six months and after that the seizures started again. So we had to fly back to Italy. Raising money, though, was a problem. (Maha, B)

⁸⁹ The seizure focus is the site in the brain from which the seizure originates and is most likely equivalent to the epileptogenic zone, defined as the area of cerebral cortex indispensable for the generation of clinical seizures.

Many mothers in both countries also commented on the lack of care in hospital, as Rasha typically describes:

The Autism Centre asked me to go to one of the well-known hospitals, and gave me a doctor's name for Sami's report. I managed to go see the doctor who gave me a report that Sami had autism. Yet, she did not apply any tests on Sami, she barely looked at him, the whole visit did not even take five minutes. (Rasha, SA)

Noor in Bahrain commented on the lack of sympathy:

The doctor who told me the result was not kind. On the contrary, he said to me that my son may never speak, or react to me. I understand that these symptoms are part of the disorder, but there is a better way of saying things. I replied to him that nothing is impossible, and just like God put this disorder in my son, only God can take it away. (Noor, B)

Even though Warda went to Kuwait to seek her son's diagnoses, she was not happy with the care the hospital provided:

In Kuwait we weren't treated professionally. The doctor spent less than an hour with Taher, then handed in the report that he has autism. I told her I refused to accept this diagnoses, not because I am an ignorant mother, but because she had no right to label my son in such a short time. (Warda, B)

Nora experienced medical incompetence:

When Ahmad was a new-born one of the doctors damaged his testicles by pressing them. So I had to operate on Ahmad when he got a bit older to fix the problem. This operation cost a lot of money, which I managed to get from my father's inheritance since my husband refused to pay for it. (Nora, SA)

As for Rana, her struggle was with the medical procedures:

I called my uncle who is a doctor, and he recommended one of his well-known colleagues who specialised in developmental disorder. I arranged for an appointment and I went with my husband to see her. At the first appointment, the doctor said she couldn't diagnose Yazeed in one session, and that he needed to attend several sessions. She also transferred us to see a neurologist. We had to overtake MRI⁹⁰, CT⁹¹ scan and so on. Since he wouldn't stay still they had to sedate him. This entire experience wasn't pleasant and he suffered a lot. (Rana, SA)

⁹⁰ Magnetic resonance imaging (MRI) is a type of scan that uses strong magnetic fields and radio waves to produce detailed images of the inside of the body.

⁹¹ A computerised tomography (CT) scan uses X-rays and a computer to create detailed images of the inside of the body.

In some cases, the hospitals did manage to provide useful information. Rana, explained: *After a month of sessions and examination, we receive the final diagnosis that Yazeed has autism. My son was about 3 years' old, and the doctor told me about a well-known Autism Centre in Makkah where I enrolled Yazeed. (Rana, SA)*

Asma'a, Samia and Noor all had similar experiences. For example, Samia said: *We waited until Fahad became about two year's old. We took him to the doctor and he was diagnosed with autism. Yara was easier to notice compared to Fahad, since Yara's blood tests and screening showed she had a problem. When we went to the States Fahad was about five years old, and we did all the blood tests and screening but the diagnosis didn't change. He had autism and was non-verbal. (Samia, B)*

In some cases described here, doctors and hospitals failed to offer any information on autism after it was diagnosed, and this left the mothers feeling confused and rather helpless. As Nouf put it so well: *'I was lost'*. Even when some hospitals eventually diagnosed autism, few hospitals provided advice about support and their role seemed to be that of diagnosis only with a number of my mothers feeling the need to travel overseas for additional tests and support, as noted above. Autism Centres sometimes provided diagnosis and I will discuss now another type of formal support, from schools and Autism Centres.

Schools and Autism Centre Support

Some mothers enrolled their sons in specialised Autism Centres, while others preferred general schools for integration purposes. Some mothers were forced to send their sons to other countries such as Jordan and Egypt due to a lack of available services for adolescents with autism. In other cases, the adolescent ended up staying at home because his parents did not have the financial resources to enrol him in an Autism Centre since all Autism Centres are private (see Table 6.8, Appendix Five). Professional educational support provided in Autism Centres and specialised schools, which have trained staff and proper teaching aids for individuals with autism, is critical (Wilkinson & Twist, 2010).

Because many mothers in Saudi Arabia struggle with mobility and the male guardianship law, as I explained above and in Chapter Two, some could not access schools. Three mothers could not take their sons to school because they could not drive or hire a driver, or did not have the required consent form for their sons' enrolment. Fatima, one of the

mothers who struggled with sex segregated schools and consent forms, described her situation as follows:

Once I went to my son's school to talk to the class supervisor. The doorman went in and called the teacher, and then the teacher came out and told me the supervisor would be with me in five minutes. I waited in the heat for more than an hour and no one came, so I had to take a taxi and go back home. I cannot enrol my children into schools without the signature of their father since he is the male guardian of the family. However, because I am in the process of getting 'Sak i'eala'a'⁹², the school accepted my older son's signature. (Fatima, SA)

Nora is another mother who experienced many challenges because of the rules and regulations in Saudi Arabia:

I called the school and talked to the teacher and told him that Ahmad is very excited to come to school, and he waits outside the house every morning for the driver to pick him up. But the teacher yelled at me and said "We do not talk to women. Have your husband come and talk to us!" and he hung up the 'phone. Then I tried so hard with Ahmad's father to go to school and talk to them but he would not go. So Ahmad is staying home again, and I do not know what to do. After that, I found a disability centre for Ahmad when he was about 10 years old and went with him daily where he was properly trained for many things such as using the toilet, using a pen and recognising shapes and letters. Ahmad stayed in the disability centre for almost two years, and then they told me that he could not come anymore because he had turned 12 and was considered too old to be in a woman's centre. (Nora, SA)

Nada is also unhappy with the sex segregated system:

Adel is in a sex segregated school. I have no access to the school. Yet, I call and threaten them that I am coming so they would get scared and treat my son better. One time I found out that the teacher hit Adel, so I called the school and said "I don't care about your rules and regulations and I will come to the school myself if you ever treat my son like this again". When I was in the States, I did my research on my son's case, which is why I needed to observe him while in school. For me to gain access to his school, I had to go to the FBI first for fingerprints even though he is my son. (Nada, SA)

⁹² An official deed, obtained from the court if the mother a widow or divorced to prove her marital status so she can have control over her children and make official transactions much easier.

Mai's son ended up staying at home because of the education system in Saudi Arabia: *When Rami reached 12, the Autism Centre opened a separate department for boys since they are not allowed to stay with female teachers. The department was really good and helpful; they hired male teachers and trained them well. Rami and so many other boys were gaining a lot by attending the centre. Unfortunately, they closed down the male department. They said the Autism Centre considered under (a Women Charitable Organisation) which is a charity organisation that works with orphans, foundlings, disabilities and poverty. Since the organisation was originally founded for females, it was not allowed to have any places open a male department of any kind. Since the department closed down about a year and a half ago, Rami has stayed at home doing nothing. He has no place to go. (Mai, SA)*

Amal, because of her good financial and social status, was able to overcome the Saudi rules:

I was able to ask the teachers to come to my place to discuss any concerns about Kareem. I was always in contact with his teachers, he had about five, and they change every year. And every year I bring the new teachers over to my place to talk to them about Kareem's situation. (Amal, SA)

However, three mothers in Saudi suffered financially: Fatima, Rasha and Nora. Fatima said:

I need to pay a driver to take me to work, take my daughter to university and take my other girl to the special education centre. I also use a taxi for other places. I found a private Autism Centre for my son, yet I am unable to enrol him due to my financial situation. I am currently saving money, though, to try to find him a place in the private centre. (Fatima, SA)

Rasha shared her similar experiences:

We do not have any public centres for autism. When Sami received the diagnosis and we had to enrol him into the centre we couldn't afford it. The centre though connected us to people who sponsor children with financial troubles. I asked the Principal of the centre to find us a sponsor. They found us a sponsor, and I enrolled Sami into the centre. After a while, they told me that the sponsor was not available anymore and that I had to pay Sami's fees. I did not want to take Sami out of the centre, so I borrowed money to pay the fees. I cannot really blame my husband for our financial situation. He wants to help keep Sami in the centre, but he works as a telephone operator and his salary barely covers our expenses. We have a house full of people; he has to provide for me, the children, his

mother, his widow sister with her child, and his older single sister. I kept looking for Autism Centres to enrol Sami, I found a couple of them. Yet, I faced the same problem with each centre - the fees. I not only have to pay the centre's fees, but I also have to pay for transportation. (Rasha, SA)

Fatima, Rasha and Mai all have their sons at home either because of financial difficulties or sex segregation.

Other mothers faced general school issues, such as bullying (Rex, 2014), lack of learning and teachers' lack of experience (Geraldina, 2015). The sons of Huda and Nada (Saudi) were mistreated by their classmates. This is Huda's experience:

Ali is older than his classmates. When they bully him or hit him and he defends himself by hitting back he gets all the blame. Parents complain how an older kid is hitting their kids even though they are the ones bullying Ali. I teach him not to hit even if they hit him. I don't want him to be expelled from school, then he will have nowhere to go. There are no alternatives. Our education system is very poor and all schools are the same. Also I do not want to take Ali to an Autism Centre. At least he is in a school even if he is not benefiting from it. Taking him back to an Autism Centre feels like he is going back to ground zero. (Huda, SA)

Nada, as an Autism Centre Principal, advises mothers to leave the country if they have the financial ability to do so because she believes Saudi Arabia does not have good schools for individuals with autism, and she shares her experience of bullying:

Regardless of the fact that Adel goes to an expensive private school, he was treated in a very bad way. One time, his classmates offered him sweets in exchange for taking off his clothes, and he agreed to it. I was shocked! His brother found out from another boy in school, came home and told me. I called the school, my husband went there and threatened to call the police and we found out who did it to him. When we knew the boys who did this to Adel, we made a deal with them: we won't complain if they will help protect him. It worked, and these boys became his friends. If someone bullied or harmed Adel, they would go to the school Principal and tell him. (Nada, SA)

Noha sent her son to Egypt and brought him back when the Egyptian revolution erupted: *After Khalid's returned from Egypt I put him in a private school specialising in disabilities. I didn't take him to this school because he is not learning anything, I simply took him because I do not want him to stay home. He brings back homework but when I go through it with him, he doesn't give me any response. I taught Khalid everything on my own: how to eat, how to use the toilet. He still does not use the toilet completely on his own, I have to go with him sometimes. The only help I got was when Khalid was in Egypt but nothing after that. I even went to one of the autism centres and asked them to offer mothers workshops on how to deal with their children with autism, but nothing happened my son is 15 years old now, and still there is nothing - these centres offer but empty words.* (Noha, SA)

Warda also struggled with schools but eventually found a centre willing to take her son: *After a while, I met a mother of a child with autism. I found out later on that she is one of the founders of a well-known Autism Centre, and her son goes there. Yet, she didn't tell me about it although she knew I was looking for a better place for Taher. The reason she was discreet because she wanted to keep the centre only for people they know! I managed to go to the centre though, and Taher was number 33 on the waiting list; now the waiting list has reached 300. I waited for their call, and Taher was accepted in the afternoon period. So I would take him to the first Autism Centre in the morning, and take him to the new one in the afternoon.* (Warda, B)

Huda's son also suffers from poor care in schools: *I know my son is suffering. One time his father went to his class to check on him in the middle of a quiz. Everyone was writing except Ali. When his father asked him why he replied, "I do not have a pen". The teacher did not bother to even give him a pen or ask him to answer the questions. They just do not care.* (Huda, SA)

Three Bahraini mothers, Asma'a, Warda and Samia, also complained about the same problem. This is how Asma'a described her son's school:

Around the time we noticed the symptoms, and obtained the diagnoses I enrolled Khan in a private preschool. They did not notice the problem at all, and did nothing to help him. (Asma'a, B)

However, in some cases, mothers have positive feedback about the centres. Huda and Mai from Saudi Arabia and Asma'a, Sana'a and Noor from Bahrain all shared similar experiences. Noor, was so upset when she learned that Waleed was autistic but the Principal was kind and sought to reassure her:

When they first told me in the centre that Waleed might have autism, I didn't know what to do and I started crying. The owner tried to calm me down, and explained to me that I should accept my son if I want him to get better. Then she directed me to go to a well-known psychiatrist who would confirm Waleed's condition. (Noor, B)

Some mothers believed that the Autism Centre was empowering their sons. Mai's son, Rami, for example, was trained to be a teaching assistant by the Autism Centre when they recognised how well he got on with young children:

Rami's behaviour became a lot better after he started going to the Autism Centre. At home, we almost treated him as if he was a typical boy. Rami's behaviour was not problematic at all. ... They started teaching him practical skills and when they noticed he was good with young children, they trained him to be a teacher assistant, and they started giving him a monthly salary for his job, until of the course the centre closed its doors. (Mai, B)

I will now turn to explore how other support institutions such as Ministries and leisure facilities were able to help these mothers.

Other Institutional Support

Mothers in both countries confronted problems from other institutions from which they might have expected to receive support. The Ministry of Social Affairs in Saudi Arabia issues child benefits and disability cards but Fatima, Nora and Rasha all struggled to obtain what they were due. Fatima, for example said:

I used to get benefits from the government for Sameer. Yet after I got my job, the money stopped even though I do not make enough to take care of my children. (Fatima, SA)

Nora had to endure mistreatment from an employee:

He was extremely rude to me and said "if he is going to write in the report that Ahmad could benefit from attending the school, they will cut off his allowance". I told him "I do not care about the money, I only want my son to go to school and learn. I want him to be happy when he goes to school and plays with children of his age. And if my son's survival is dependent on your money, I do not want it". He wrote me what I asked for, but not without threatening me that they would stop the allowance. (Nora, SA)

The issue of male guardianship, as I have stated in this chapter (and see Chapter Two) is an issue mothers face in Saudi Arabia whenever they deal with official institutions such as the Ministry. Nothing can be done without the presence of the male guardian. Nora's financial situation was not taken into consideration when she was rejected for benefits:

It has been almost two months without money, money I need not only for Ahmad, but also for my other children. I tried to explain to them my situation and how much I need this money, and how I do everything by myself. They just would not listen; they insisted that my husband should come to renew the disability card. (Nora, SA)

Sarah from Saudi and Maha from Bahrain were affected by their workplaces. Sarah shared her experience:

I consider myself lucky. I used to attend lectures and expeditions held by my university where I learned a lot about autism. So, with the help and support of my work, I taught myself how to help and handle Maher. (Sarah, SA)

Maha, on the other hand, had a negative experience with her workplace which she managed to turn into a positive one. On a whim she called a radio show and was given the opportunity to speak to the Minister of the Interior:

I used to work in a private company that refused to give me enough holidays to visit Amir. One morning, while I was driving, I decided to call this well-known live radio show. Surprisingly, they answered me and I told the interviewer that I have a message for the Minister of the Interior, she said go ahead. I talked about my entire situation on air, that I work in a private sector and I couldn't visit my son for almost four months, and that I wanted the Minister to consider my situation as a Bahraini citizen who is in need of a governmental job. Five minutes later, the Security Media called me asking for my papers saying they received a direct order from the Minister to offer me a job in the Ministry of the Interior where I have been working for five years now. I know some people talk behind my back saying that I use my son's situation to get what I need, but only God knows what is in my heart. (Maha, B)

Maha was fortunate and the outcome of speaking to the Minister was better than she had hoped. Warda's experience was quite different. Her son, Taher, is in Jordan because she found it difficult to find an Autism Centre that would help the family. Warda sought help from the Bahraini Ambassador to Jordan. His response shocked her:

I tried with the government to pay for Taher's expenses in Jordan. They replied that they cannot sponsor children with autism, since it is a life-long disorder and there is no cure for it. ... I also had several conversations with the Bahraini Ambassador in Jordan asking him for help, but it didn't work out. The ambassador's advice actually shocked me, he said "check where the Prime Minister's whereabouts and go wait for him in the streets and try to talk to him about your son's situation". I left the embassy annoyed and thinking to myself "this is a street fight! Where are the rules and the regulations? What is the role of The Ministry of Social Development and the Ministry of Education?" (Warda, B)

Accessing support networks is difficult in both Saudi Arabia and Bahrain. Sarah, Noha and Rana from Saudi, expressed their disappointments with lack of activities for their sons with autism.

We do not have any proper activities for Maher to do. I thought about sending him to summer camp, but I did not find anything trustworthy in Saudi Arabia. People who handle them are usually untrained. (Sarah, SA)

Noha has a similar view:

We have nothing here. No one cares about our children, no social institutions, no decent centres, no support or help, especially children with autism, since they look normal. People expect them to act normal. They simply do not understand our daily struggle with the disorder There are no suitable gyms, and even if there are good ones, I cannot take him. At his age, he is not allowed into girls' gyms and I cannot enter men's gyms. There is nothing for families, and usually fathers do not take their children, it is mostly the mother. (Noha, SA)

Formal support provided by professionals in hospitals and schools mostly failed the mothers in my study. Mothers who could afford it had to travel to other countries to obtain a correct diagnosis for their sons. It was difficult to find schools and Autism Centres that could meet the needs of adolescents with autism. Although most of my Bahraini participants enrolled their sons in a good Autism Centre during their childhood, the same centre could not accommodate their needs as adolescents which is why some mothers were forced to send their sons to boarding schools in other countries, as I explained above. The

difficulties the mothers encounter stem, in large part, from poor understanding of Autism Spectrum Disorder. In the next section, I will discuss how societal support affects the mothers' capacities to include their sons in society and as I do so, keep in mind that the social model of disability 'proposes that what makes someone disabled is not their medical condition, but the attitudes and structures of society'⁹³.

Societal Support

Societal support includes awareness, others' reactions to autism and the availability of social networks (see Table 6.9, Appendix Five) . In a study by Smith et al. (2012), having a supportive social network increased well-being. Educating the public about autism also improves others' attitude towards the disorder (Martin & Bassman, 2012) and might affect the sort of societal change called or, as noted earlier, by those working within the social model of disability.

Noha, Nada and Mai all believe society lacks awareness of autism. Noha said:

People act as if they have never heard about autism before although everyone is talking about it nowadays. Many people look at my son as if he is some strange creature. Their looks are annoying and make me feel uncomfortable. Khalid does strange moves sometimes when he laughs, and he flaps his hands so even people who work in the shops leave their work and stare at him. (Noha, SA)

Nada had a similar point of view:

I expected to come back to Saudi to find more awareness of autism. Unfortunately, I still meet people who never heard about autism. I wasn't living in a big city in the States, yet everyone knew what autism was. They did a lot of social activity for awareness and involved Adel as well. For example, they would ask for my permission to publish a video of Adel on YouTube! (Nada, AS)

⁹³ <https://www.mentalhealth.org.uk/learning-disabilities/a-to-z/s/social-model-disability>

The mothers in this study bear the burden of providing care for their sons with autism, and many of them struggle with a judgmental society that lacks awareness of their feelings as mothers of adolescents with autism, as the data revealed. Behaviours such as staring and laughing hurt not only the mothers but their sons as well. Mothers' responses to these negative reactions varied. Some, for example, decided to take action by raising awareness of autism and being active in events and support groups. This is how both Warda and Nada reacted, an experience Warda shares:

I am the head of an awareness committee in Bahrain. We work hard to spread awareness about autism, and we form a support for new mothers whose kids have just received the diagnoses. We talk to them about autism, explain to them what to expect and offer help. We also go to shopping centres in Bahrain, handout brochures about autism on our own expense to spread awareness. We would visit hospitals and explain to them about autism. Because Bahrain is small, it is not that hard to spread awareness, and our 'phone numbers are available to anyone who needs help and wants to know and learn about autism. Basically, we started to the support system in society. (Warda, B)

Others decided to completely ignore society and not pay attention to what people said like Sarah. Some reacted by challenging people's reactions, like Nora, who simply yelled at the girls who laughed at her son because she took him to the ladies' washroom. Samia, on the other hand, understood why some people would react negatively to her son:

As parents of children with disability, we should also be sensitive towards others. For example, why should a person sitting in a restaurant for dinner tolerate my son's shouting and screaming? It is not fair. (Samia, B)

By contrast, Rana has a positive point of view:

People know more about autism now. When I took my boys to play in the mall, the lady who is in charge of the games asked when she saw them if they have autism, I said "yes" ... When we were playing in the trampoline, the lady who watches the children asked me if Zaid has autism, I also replied with "yes". Then she asked the rest of the children to move to the other trampoline, and left only couple of boys with Zaid. It seemed like she knew that having many people around could bother him without me saying anything. Their reaction made me so happy. (Rana, SA)

As for Noor, she believes that awareness is increasing, however some individuals are still judgmental:

The awareness among society is increasing yet still the society is somehow judgmental ... Once, I was in the supermarket with Waleed when he was on the food diet, and he wanted a chocolate bar. Of course, I couldn't buy it for him, so an older man approached me and offered to buy it for Waleed. I thanked him but he was annoyed at me and said "don't do this to the boy, I will buy him the chocolate". Then he started yelling at me, so I bought the chocolate for Waleed so the guy would go away. (Noor, B)

Unsurprisingly, some of the mothers told me that social attitudes towards them as women, and as mothers of children with disabilities was challenging, if not hypocritical. Sarah, from Saudi Arabia told me that '*Our society is built on hypocrisy, people do everything they want, they just do them secretly*'. As a divorced woman, Maha felt she was a victim: *A divorced woman in our society, especially if she has a disabled child, is a victim. With no man for backup, and with financial issues, people think it is easy to take advantage of me. At times, it feels like people are waiting for me to fall but I won't give this chance to anyone. I will keep taking care of my son and do whatever is necessary to give him the proper life he deserves. This is not just my case; this is the case of every mother who has a life similar to mine. (Maha, B)*

All mothers agreed that people who do not have a child on the spectrum do not understand their situation. For example, Warda said:

I believe only people in our position understand what we go through. If I tell one of the other mothers I didn't sleep at night, she will understand why I didn't sleep unlike if I say this to someone who doesn't have a child with autism. Other people might be aware of autism and understand the disorder, but they will never comprehend the feelings and the emotions we struggle with. (Warda, B)

Rasha, with few financial means and lack of family support, experiences loneliness and oppression. The role of male guardian again plays a major role in Rasha's ability to help Sami. She could not apply for government's sponsorship on her own and could not renew his disability card. Rasha could not even request benefit increases. Although, in most cases, mothers are the primary caregivers, they do not have the full ability to fulfil their children's needs due to the norms and regulations within Saudi society. With no support from the

male members within the family, and not being allowed to drive, lack of mobility is also a hindrance, since paying for transportation was the main reason for not enrolling Sami in an autism centre.

Many of the Bahraini mothers' experiences were different from the Saudi mothers, especially with respect to mobility and sex segregated centres. Mothers in Bahrain can drive their own cars. For example, when I asked Asma'a about transportation she didn't seem to have a problem at all. She replied: *'Usually his father drives him to the Autism Centre, but when he is busy I take him myself'*.

The social network of a mother can play a significant role in support. For example, the roof of Fatima's shanty fell in. She could not move to another place without the help of wealthy people who found her a small flat for which they paid for rent and house bills every month. In Saudi Arabia, this is a very common practice, where a wealthy family takes care of a less fortunate one. In some cases, wealthy families build flats and distribute them among poor people free of charge. Other families offer to take care of bills, food and monthly allowance, and in Fatima's case, rent.

6.4 Summary

This chapter presented a thematic analysis of the mothers' experiences with social support including informal support, the support of the spouse, family and friends; and formal support which covers hospitals, schools, other institutions and society. Unfortunately, many mothers struggled with a lack of support which increased their level of stress and promoted negative affective responses. By contrast, the mothers who had supportive spouses and family members, for example, talked of more positive feelings. Talking of the individual and social models of disability, decades ago Oliver warned that care should be taken not:

... to spend all of our time considering what we mean by the medical model or the social model, or perhaps the psychological or more recently, the administrative or charity models of disability. These semantic discussions will obscure the real issues in disability which are about oppression, discrimination, inequality and poverty. (Oliver, 1990, p.1)

In the following chapter I will turn to such issues of justice as I analyse mothers' experiences using Nussbaum's ten central capabilities, a central feature of Nussbaum's version of the Capability Approach.

Chapter Seven: The Capability Approach

If our world is to be a decent world in the future, we must acknowledge right now that we are citizens of one interdependent world, held together by mutual fellowship as well as the pursuit of mutual advantage, by compassion as well as self-interest, by a love of human dignity in all people, even when there is nothing we have to gain from co-operating with them. Or rather, even when what we have to gain is the biggest thing of all: participation in a just and morally decent world.

Nussbaum, 2006, p.324

7.1 Introduction

In this chapter, I will analyse my interview data with respect to the Capability Approach to examine mothers' experiences of their society, families and their adolescents with autism. In addition, I will examine the extent to which the mothers in this study are able to realise each of the ten central capabilities, a central feature of Nussbaum's version of the Capability Approach as outlined in Chapter One. This analysis will reveal the extent of gender inequality which, if we are to create the 'just and morally decent world' to which Nussbaum (2006, p.324) aspires, must be acknowledged and addressed for the sake of women themselves and their community. Gender discrimination can lead not only to women's abuse and mistreatment, but can negatively affect the development of an entire community or country by failing to allow women to be fully participating human beings, not merely women who, so often, are the primary carers in almost every family in Saudi Arabia and Bahrain. As Nussbaum states in the epigraph above, a moral and ethical society based on equal respect is the goal and I argue that analysing the extent to which the mothers I interviewed might or might not reach that goal requires an engagement with concepts such as justice, well-being and quality of life. In the next section, I will start the analyses of the data using the ten central capabilities.

7.2 The Participants and the Ten Central Human Capabilities

The Capability Approach does not only focus on what individuals regard as satisfying but, rather, on what they are capable of doing and being, especially when given appropriate opportunities in their society. The approach as Nussbaum describes it 'is concerned with entrenched social injustice and inequality, especially capability failures that are the result

of discrimination or marginalisation’ (Nussbaum, 2011, p.19). A just society, according to Nussbaum (2006, p.75), should provide its citizens with ‘some appropriate threshold level’ of the ten capabilities each of which is inter-dependent. They are also non-fungible, meaning that one capability cannot be traded for more of another. Each capability should be developed in order to provide the citizens of any society with a life of choice and dignity, a life worthy of living, in which ‘a given liberty is implicated in the idea of human dignity’ (Nussbaum, 2011, p. 32).

Nussbaum also tackles the issues of women’s acceptance of their situation as I discussed above. Since Saudi Arabia is a religious society, arguably some women fear that change would jeopardise their religious values. In addition, and as Nussbaum has acknowledged, such women may fear that change will make things worse (Nussbaum, 2000, p.43). During my interviews with the Saudi mothers, we discussed their feelings about their lives including what changes they needed to have a better life. Most of them showed contentment and satisfaction, such as Fatima: *‘We are just doing fine and not in need for anything or any change’*. As I explained with respect to adaptive preferences, Saudi women are made to accept their situation to the extent that they develop a sense that their norms are natural, or of hopelessness that nothing can change.

Discussion of the data will be organised against each of the capabilities but will not follow Nussbaum’s order. Rather, I will organise the discussion according to the most dominant capabilities to emerge from the interviews, and by Saudi mothers’ experiences in particular. The original order and complete list of the Capabilities in Appendix Four.

I begin with Capability 3 because it features so prominently in the interviews with Saudi mothers. Capability Three is:

Bodily integrity. Being able to move freely from place to place; to be secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction (Nussbaum, 2006, p. 78).

While Bahraini mothers can legally move freely from place to place, Saudi mothers cannot. There is also very little public transportation and mothers find themselves in

a very difficult situation if they do not have a supportive male family member or do not have the financial resources to hire a driver. By contrast, freedom of movement for mothers in Bahrain is such a basic liberty that the issue is which school their child will attend, not how the child will get to school. As Warda explained: *I used to drive around in Bahrain looking for Autism Centres in which to enrol my son*’. Sana’a also drove her son to school: *When Saleem was younger I used to drive him to the centre myself. I didn’t like sending him off on the bus since he was still young. (Sana’a)*

The lack of this capability has a major effect on mothers’ lives with respect to accessing necessary support. When a woman lacks the right to move freely, when she cannot take her son to a hospital for example, or to school, unless her husband, male guardian or driver will take her, this is capability failure – and it restricts her choices greatly, even to the extent of not being able to leave an abusive relationship. Rasha’s, Nora’s, and Fatima’s low incomes mean that they cannot afford to hire a driver which increases their struggles to get their children to school or elsewhere. Huda and Mai are fortunate as they have spouses who are willing to drive them. Sarah, Amal, Noha, Nada, and Rana have the financial means to hire a driver, so they do not suffer from mobility issues to the extent that the less well-off mothers do, and are less dependent on their husbands.

Nora (Saudi) exemplifies how, in her case, infertile functioning of aspects of Capability 3, being free to move safely from place to place, can have serious quality of life issues for her and her child. As she said:

I finally found a disability centre that Ahmad could attend but I had no one to drive me. I asked my husband for help but he told me to handle it on my own. (Nora, SA)

Nora not only experienced corrosive functioning with respect to mobility, but also lacked security against violence and domestic abuse by her abusive husband, an aspect of Capability 3 for which fertile functioning is essential for a flourishing life:

He hit me and divorced me, but I had to come back to him for the sake of my children and for Ahmad. (Nora, SA)

In this case, even if Nora decided to leave her husband, she would not be able to rent a flat, apply for benefits or seek a job without her male guardian’s consent. As an adult woman she is accorded no freedom to make her own choices in matters as fundamental as these because she is legally regarded as no more competent than a child. This is an example of

how threshold levels of functioning can be limited: choosing where to live, choosing her profession, choosing to leave an abusive husband, or collecting benefits on behalf of her child. In Saudi society, women have so few freedoms that they have to return to their family for security, assuming they are secure from violence, abuse or neglect. Nussbaum (2011) describes the same kinds of problems for poor Indian women who have to return to their parents' homes when they divorce but in many cases, especially in poor families, to accept a woman back into the house means an extra person to feed which is considered a burden. Nora, who does not have parents, would have to live with one of her brothers who are already married and have families of their own.

As for sexual assault, development of this capability can also be threatened by mere restriction on movement. Nora and her daughters, for example, had to deal with verbal-sexual assault from her driver:

The driver who drives my daughters to college happens to be one of our neighbours, and has a bad reputation. He verbally sexually assaulted me when he used to drive me to the centre with Ahmad. But, unfortunately, he is the only one available to take the girls to university. I told their father, and he said "Just ignore the man and if he does not stop, keep the girls at home". So I told him that it had stopped because I really wanted my daughters to complete their education and graduate. I do not want them to end up like me, so I told their father that the assaults had stopped. (Nora, SA)

Nora's bodily integrity is also compromised because she has no control in matters of reproduction:

We have four children and I told my husband we had enough, but he insisted. Although I know he is not faithful to me, I couldn't say no to him'. As for opportunities for sexual satisfaction: 'I cannot stand him now, I cannot stand that he touches me. I only do it because I have to, not because I want to. (Nora, SA)

Nora has no entitlement to her own body – it does not seem to belong to her. She experiences capability failure because she cannot function as an independent sexual being or in matters of reproduction. She has to endure her husband's sexual assaults, though, tragically, the notion of sexual assault does not exist in law, religion or culture in Saudi Arabia. Women's lack of resources to understand what is happening to them constitutes an adaptive preference in that they have learned to tolerate the intolerable.

Fatima, another Saudi mother, suffered domestic violence before she managed to get a divorce from her abusive husband. Rana's threshold level of functioning for sexual satisfaction is below what is desirable, or dignified, since her relationship with her husband is based on fulfilling her duty towards him:

He always nags about having a healthy boy. He even said he wants to marry another woman just to have him. My husband and I have lost each other. We barely talk and, when we do, it is all about the children. I come to his home to fulfil my duty towards him and to be with my children. I do not feel I am coming back to my husband anymore. (Rana, SA)

Lacking the basic opportunity freedom to drive or to move freely without either the consent of, or being accompanied by, a male guardian, takes us naturally to Capability 7, Affiliation, which Nussbaum explains as follows.

A. Being able to live towards each other, to recognise and show concern for other human beings, to engage in various forms of social interaction; to be able to imagine the situation of another. (Protecting this capability means protecting institutions that constitute and nourish such forms of affiliation, and also protecting the freedom of assembly and political speech.)

B. Having the social basis of self-respect and non-humiliation; being able to be treated as dignified being who is worth is equal to that of other. This entitles provisions of non-discrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion, national origin (Nussbaum, 2006, p. 78).

Since freedom of movement is restricted in Saudi Arabia, the extent to which mothers are free to affiliate is compromised, as I will shortly discuss. To begin with the fertile aspects this Capability functioning, it is true that mothers in both countries were 'able to live with and towards others, and to recognise and show concern for other human beings', not only towards their sons, but also towards other mothers of individuals with autism. Sana'a was one of the founders of a parents association for children with disability:

We had a good group of parents who were working together. We were not only helping our children, but also supporting each other through difficult times. We used to arrange for meetings, talk to new parents and help them through the beginning of the disorder. We also would gather to discuss new information and training about autism. (Sana'a, B)

Warda (Bahrain) is also in charge of an awareness committee in Bahrain that works to spread awareness about autism, and support for new mothers who just received their children's diagnosis. However, mothers in my research often lack the ability to engage in various forms of social interaction unless they engage with other mothers who share similar experiences, but the threshold at which many of the mothers can realise this capability may not always be consistently available or possible. Fortunately, Maha has supportive relationships with other mothers:

Many mothers who suffer the same issue as mine supported me. Mothers understand what I go through with Amir, since they share my situation. (Maha, B)

This is an important source of social support, coming as it does from other mothers of stigmatised adolescents. However, with regard to more general social interaction, many mothers were socially isolated because of their sons' difficult behaviour since there are few if any social structures to support the mother and permit social interactions and because the mothers are continuously with their sons. Rana, Mai, Rasha, Amal, Sarah (Saudi) live in isolation, as Rana, for example, explains: *I stopped going out, stayed away from everyone, including relatives and friends. I decided to dedicate myself completely to my boys. (Rana, SA)*

Amal, like Rana, has had similar experiences in achieving fertile functioning with respect to Affiliation:

It was just me and Kareem - he is the centre of my life. I had no friends, no social life. I couldn't go out or do anything. I was always with my son. He has no one but me. (Amal, SA)

Rasha describes how her capability to affiliate meaningfully with others is not available to her, primarily because she lacks familial support:

People wonder why I do not have a social life - why I do not visit my cousins and my neighbours. When they come and visit me, and see Sami's condition, they are shocked. They do not expect him to be that bad. And of course I cannot take him anywhere with me and I cannot leave him behind either. So I simply end up staying home with him. (Rasha, SA).

A further example of mothers' isolation comes from Nouf who decided to leave a family gathering because of her son's autism:

It is a weekly habit to visit the family for lunch. Sultan would sometimes touch his private parts in front of everyone, and they have little children who are mostly girls. When this

happens we take him to the toilet and wash him with cold water. If this helps we stay, otherwise we would leave the gathering and drive back home. We don't want anyone to feel bothered by our son, so whenever we notice something like this we simply leave. Although Sultan knows this behaviour is inappropriate, I believe he does it sometimes out of boredom. When he finds himself around all these people and no one is talking or interacting with him, he ends up touching himself since he has nothing else to do. (Nouf, B)

As for having the social bases of self-respect and non-humiliation, and being treated without discrimination, fundamental aspects of the capability of Affiliation then, according to their mothers, most adolescents with autism were humiliated by lack of social awareness, and when the boys were humiliated, their mothers also felt humiliated. Mothers were also discriminated against because of their sons' autism. Maha (Bahrain), for example, was unable to stay in her job because the company refused to give her holidays to go visit her son in Jordan. Many mothers also have to tolerate a lack of social awareness or compassion that may take the form of pity or condescending looks as Noha, Nada, Mai, Rasha, Huda, Nora, and Amal (Saudi) testify. This is Noha's account:

People look at him like he is this strange creature. Their looks are annoying and make me feel uncomfortable. Khalid does strange moves sometimes when he laughs, and he flaps his hands so even people who work in the shops leave their work and stare at him. (Noha, SA)

Mai, too, has to suffer the indignity of what seems to be her family's insensitivity towards her son:

My family talk about Rami with him around. They act like he is deaf or does not understand what they say. (Mai, SA)

Nouf, Warda and Sana'a (Bahrain) recount similar experiences. Here, for example, is Sana'a's experience of protecting her son against disrespectful behaviour:

People used to annoy me by the way they looked at Saleem, but it doesn't matter to me anymore. Now I only think about my son, but still I cannot take him everywhere. People sometimes make comments and I don't want his feelings to be hurt. (Sana'a, B)

What Sana'a is expressing here is also linked to Emotions, Capability 5, since other people's behaviour upset her that she avoided those who could hurt her son's feelings. Although mothers in both countries experienced poor functioning of Capability 7, it was exacerbated in Saudi Arabia by the social arrangements in the country, as I noted above. Failure to realise Capability 7 had a simultaneous impact on the realisation of Capability 10, Control over One's Environment, the definition of which is set out below:

- A. Political. Being able to participate effectively in political choices that govern one's life; having the right of political participation, protection of free speech and association.
- B. Material. Being able to hold property (both land and movable goods), and having property rights in an equal basis with others; having the right to seek employment on an equal basis with others; having the freedom on unwarranted search and seizure. In work, being able to work as human being, exercising practical reasons and entering into meaningful relationships of mutual recognition with other workers (Nussbaum, 2006, p. 78).

Saudi mothers' interviews revealed that they had far fewer opportunities to flourish in this area than had the Bahraini mothers in my study. Although both Saudi and Bahraini mothers have little control over their environment due to the characteristics of autism and lack of social awareness, this is particularly acute for mothers in Saudi (and this capability is closely linked to Capability 3 - freedom of movement, and Capability 7, discrimination on the basis of gender) since, as noted, Saudi society is governed by strict cultural customs with gender biased laws built on gender hierarchy.

Another significant issue in Saudi society that restricts the capabilities of the women in my study (and, indeed, all women in that country) is sex segregation, another law over which mothers have no control and from which many suffer. Rana shared her experience about a sudden change in her son's behaviour towards school. She was uncomfortable with such a change but according to Saudi law she can have no access to her son's all boys' school.

I kept nagging my husband to go to check what is happening but he didn't go. I even sent a thank you letter to Yazeed's teacher saying that I appreciated his efforts with Yazeed, and that he loves to come to school now, and would you please explain to me what you did to change his attitude. I sent the letter with our driver and I asked him to give it to the teacher, but I didn't receive a reply. (Rana, SA)

The only way Rana could communicate with the school was by letter but had to trust her driver, a male, to deliver the letter, and hope that the school would respond. Having no reply from the school, Rana had no power to do anything further without the intervention of her husband, who, as I explained in Chapter Six, took little interest in his son's well-being.

The male-guardianship law, another form of discrimination against women, is also linked to Capability 7, Affiliation, and, again, Saudi women have no control over this law. In public, and within social institutions, women are disabled from equally representing themselves or their interests, or from asking for what should be theirs by basic human entitlement. Once more, Saudi Arabia's social arrangements mean that functioning at this basic threshold level of functioning is not possible. During the interview, Nora said that the disability card, which she uses to claim benefits, expired several months previously and that she could not get the allowance. When she applied to the Ministry of Social Affairs to renew the card, they refused to do it without the presence of her male guardian.

It has been almost two months without money, money I need not only for Ahmad but for my other children as well. I tried to explain to them my situation and how much I needed this money, and how I do everything by myself without the help of my husband. They just would not listen - they insisted that my husband should come to renew the card. I do not know when he is going to go. (Nora, SA)

A further lack of control over one's environment is evident when mothers here talk about how their behaviour is affected by their environment. When mothers cannot control the environment in which they experience, or are likely to experience, negative and insulting behaviours, mothers may choose isolation which affects Capability 7 - Affiliation, limiting their opportunities to engage in various form of social interaction. Lack of awareness of autism and the stigma that still affects how others see persons with autism (or disability) may result in negative emotions when mother's sons are treated badly or insensitively.

My main problem was with the people around us. Whenever we go out with Khan, people stare at us - it seems like they don't understand what autism is. For example, I remember one time when we were travelling to Kuwait, Khan was making noises on the plane when one of the passengers started making comments about him which really hurt me. (Sana'a, B)

By contrast, Nada, as a Principal of an Autism Centre in Saudi, managed to gain some control over her environment by participating in awareness spreading activities such as giving out leaflets about autism in shopping malls and events. Nada also visited private schools to discuss autism and proposed establishing integrated classes for children with autism so they could be accepted in mainstream, schools and not just in Autism Centres. Similarly, in Bahrain, Warda is one of the founders of a Bahraini mothers' 'committee' group that provides support for mothers of children who have recently been diagnosed with

autism, explaining to them what to expect from their children and to educate them about the disorder. Just like Nada, Warda is also involved in events that spread awareness about autism, as I discussed in Chapter Six with respect to social support.

I will turn now to the remaining capabilities. Capability 1, the first on Nussbaum's list is: 'Life. Being able to live to the end of a human life of normal length; not dying prematurely, or before one's life is so reduced as to be not worth living' (Nussbaum, 2006, p. 78). The mothers I interviewed in both countries are predominantly middle class if class is understood with respect to occupation and education. The exceptions were Fatima, Rasha and Nora (Saudi) who come from poor socio-economic backgrounds, and Noha and Amal (Saudi) who come from affluent backgrounds. None of the mothers described their lives as not worth living and it would be premature to suggest that any of the mothers will fail to live a life of normal length although stress, arguably, could take its toll on some and in some interviews I did have the impression that some mothers occasionally felt their lives to be reduced.

I turn next to Capability 2, 'Bodily health. Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter' (Nussbaum, 2006, p. 78). Mothers in both countries do not have environmental factors that prevent them from leading a healthy life and yet two of them, Nora (Saudi) and Warda (Bahrain), face some physical issues due to their stressful situations. Nora developed diabetes and high blood pressure because of the stress she experienced at her husband's behaviour: *I am diabetic, and I have blood pressure and I do not want to lose my health for him. My children need me. (Nora, SA)*

Warda is the only person taking care of her adolescent with autism, again without any support from her husband, and her inability to control her son's behaviour is increasing as she and her son grow older:

I am not as strong now as I used to be. The Warda who was able to pick up Taher from the ground isn't there anymore. I have back and knee problems, and my son is a grown boy now. It is not as easy as it used to be. I actually tell him, 'Your mother isn't as strong, so don't hit me and don't throw yourself on the ground'. He replied 'am I a good boy'? I said 'yes, you are!' (Warda, B)

Further, mothers in both countries are able to have adequate nutrition and to have adequate shelter except Fatima (Saudi) due to her financial circumstances. Fatima is an orphan who comes from a very poor background. She used to live in a shanty dwelling in an old neighbourhood (one room and a toilet) with her five children. One day the roof of her shanty collapsed and, due to her low salary as a housekeeper in a girls' college, she could not move to another place without the help of wealthy people who, as explained in Chapter Six, found her a small flat and paid the rent and house bills every month. The financial situation has a significant effect on the mothers as I noted in Chapter Six. Fatima has three adolescents with disabilities, yet she does not have the financial ability to hire help. By contrast Samia (Bahrain), for example, has two nannies to help care for her adolescents who are both disabled.

While the mothers were generally well nourished and had access to adequate shelter, their bodily health is closely linked to Capability 5, Emotions which Nussbaum defines thus:

Being able to have attachments to things and people outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to love, to grieve, to experience longing, gratitude, and justified anger. Not having one's emotional development blighted by fear and anxiety. (Supporting this capability means supporting forms of human association that can be shown to be crucial to their development (Nussbaum, 2006, p. 78).

To begin with the positive aspects of emotional health, all mothers have attachments to their sons; they love them, care for them and grieve at their absence. The mothers' emotional states fluctuated according to their understanding of the disorder, the support they have, and the services available for their sons, as they described during the interviews (see Chapters Five and Six) The emotions the mothers had with respect to their sons before the diagnosis were negative, yet after the diagnosis some of them felt relieved, such as Sarah, Mai, Nada (Saudi), Asma'a, Maha (Bahrain), and Sana'a (Bahrain) felt blessed and happy as I explained in Chapter Five. Also, the mothers' interviews indicated that they experience longing, gratitude and anger. As they shared their stories with me, especially Warda and Maha (Bahrain) who had sent their sons to Jordan, they longed for their sons to return. Warda even brought her son back from Jordan hoping that the Autism Centre in Bahrain would be suitable for her son's needs:

I actually brought Taher back and he started going to the centre daily. Then they started making up excuses such as he is big and we cannot control him. They would call me to go to pick him up when he had his tantrums. Finally, I said to the guy, 'You proved that you can only handle babies, and young children but you cannot deal with older boys... . I started telling him names of our Bahraini kids who are in Jordan, and I said 'You want us to bring our children back from Jordan, with the way you are handling things it wouldn't be possible'. I had to take my son back to Jordan. (Warda, B)

Here we can see that Capability 7, Affiliation, is compromised because the Autism Centre is able only to care for children with autism and is unable to cater for adolescents. This, I suggest, is a problem of the system which, currently, does not offer support to young people with autism after the age of, often, sixteen or seventeen.

The mothers' emotions well-being in turn directly affects Capability 4, Senses, Imagination, and Thought which is described as:

Being able to use the senses, to imagine, think, and reason- and to do these things in a "truly human" way, a way informed and cultivated by an adequate education, including, but by no means limited to, literacy and basic mathematical and scientific training. Being able to use imagination and thought in connection with experiencing and producing works of events of one's own choice, religious, literary, musical, and so forth. Being able to use one's mind in ways protected by guarantees of freedom of expression with respect to both political and artistic speech, freedom of religious exercise. Being able to have pleasure experiences and to avoid non-beneficial pain (Nussbaum, 2006, p. 78).

It is difficult, as it is with all the capabilities, to separate the mothers' emotions from Senses, Imagination and Thought. All the mothers in my data were able to use their senses to imagine and think about their lives and, in particular and following my question about the future, to talk of their sons' futures. Yet, such imagination was mostly a source of fear and insecurity due to lack of adequate opportunities available for their sons. The mothers' ability to imagine and think is affected by their surroundings, social awareness or rather the lack of it, the stigma of the disorder, and the marginalisation of the mothers and their sons.

All the mothers' thoughts about the future were negative except those outlined by Noor (Bahrain) and Sarah (Saudi), who had positive imaginations for their sons' futures. Noor: 'I

believe in my son, he can go to college if he wants, progress and develop in life'. Mai on the other hand, like nearly all the other mothers, does not see a bright future:

Does having autism mean the end of the world? Don't our boys deserve a chance to have a productive independent life? There is nothing for them, no place to go and no job to do. (Mai, SA)

Negative emotions are obvious in Mai's words and this extract is linked to Capability 5, Emotions, since her vision of her son's future is marred by fear and anxiety. This is also linked to Capability 6 because forming a conception of the good when it comes to their sons' future is limited and is again blighted by fear and anxiety so practical reason is compromised.

Other mothers felt gratitude towards their supportive husbands and families. As Asma'a (Bahrain) described: *'I am grateful I have a supportive family.'* As for the justified anger, many mothers felt angry with those who were insensitive towards their sons. Nora (Saudi) is an example: *'A couple of girls were laughing at Ahmad. I was furious about their behaviour'.* This is also linked to Affiliation, Capability 7, since any humiliation for the child is humiliation for his mother, as I said above. When these girls started laughing at Ahmad, they humiliated him for though he himself may have been unaware of their unkind laughter, they failed to see him as a person, only an object to be laughed at. The mothers' senses, imagination and thoughts were often affected by fear of what will be if they die before their sons. With no one to care for them they hoped their sons would die before them as noted in Chapter Four and Chapter Six.

Capability 3, Bodily Integrity, also features here because when Warda and other mothers think about what will happen to their sons if they die, they cannot imagine what the future will hold for them. So Huda said:

Sometimes I pray to God that Ali dies before me, because I know no one will take care of him like I do. (Huda, SA)

In this study, mothers' abilities to form a conception of the good and to engage in critical reflection about the planning of their lives is also jeopardised because of social stigma, and poor understanding of autism and their sons' needs. Consequently, Capability 6. Practical Reason, was affected. Practical Reason means:

Being able to form a conception of the good and to engage in critical reflection about the planning of one's life. (This entails protection for the liberty of conscience and religious observance.) (Nussbaum, 2006, p. 78).

It was hard for the mothers to plan their lives apart from their sons as they are the primary care takers. When I asked mothers to think about their lives, they tended in fact to think about their sons, what they could do to help them, how they could make their lives better, and how to protect them from harm and ridicule, and so on. When Nouf, for example, discussed her plans, they were mostly related to her son:

Sultan loves planting, so I was thinking to buy a small piece of land where he can practise and enjoy planting but I cannot afford it. I had a small piece of land, but I had to sell it when Sultan first showed autism symptoms because we needed the money. (Nouf, B)

When Nouf shared her plans with regard to her son, she expressed his love of other species, which is Capability 8, Other Species: 'Being able to live with concern for and in relation to animals, plants, and the world of nature (Nussbaum, 2006, p. 78)'. Capability 8 is particularly relevant for two of the mothers, Amal (Saudi) and Nouf (Bahrain). Amal's son was attached to animals:

The further Kareem grows from people, the closer he grows to animals. I was helping him fulfil this passion. I hired a special trainer to help him take care of his pets. I was happy to see him doing something. (Amal, SA)

Amal believed that being close to animals helps to calm down Kareem who has many pets such as dogs, cats and some exotic animals. Indeed, many recent studies evidence the benefits of the animal assisted therapy (AAT) for individuals with autism (Burrows et al., 2008), supporting Nussbaum's claim that being able to live in relation with other animals and the environment is important to human flourishing.

A capability I believe all mothers lack in significant aspects of their lives is Capability 9, 'To laugh, to play, and to enjoy recreational activities' (Nussbaum, 2006, p. 78). They do not have the opportunities and the freedom to enjoy this capability not least because they lack Capabilities 3, 4 and 5. Also, the political and social arrangements of society do not support the mothers and their sons by providing places where they can go and enjoy leisure and recreation. There is little, if any, entertainment available for mothers and their adolescents with autism. Noha (Saudi) shared her experience:

We have nothing here, absolutely nothing. Khalid loves swimming, and I cannot take him anywhere to swim. There are no places for our children to practise their hobbies or to

entertain themselves. There are no suitable gyms, and even if there are good ones, I cannot take him. At his age, he is not allowed into girls' gyms and I cannot enter men's gyms.

(Noha, SA)

Sex segregation in Noha's case was one of the reasons she could not fulfil Capability 9, since Saudi Arabia lacks suitable places for adolescents with autism and, as noted above, Noha's son, Khalid, can no longer play in the play areas of the shopping centre because of his size. Nouf (Bahrain) also encounters difficulties finding leisure facilities for her son or anyone with disabilities:

In Bahrain we have many sport centres; each village has one. Yet no one cares about providing anything for adolescents with autism. In fact, all disabilities are ignored, not just autism. No one ever thought about arranging one day a week for these teens to go to the sport centres and enjoy their time like their peers. (Nouf, B)

I noted that capabilities are 'opportunities or freedoms to achieve what an individual reflectively considers valuable' (Walker & Unterhalter, 2007, p. 2). While all people, women included, ought to be able to live a dignified life shaped by their own choices and freedoms, yet the human capabilities of the women in my study are jeopardised because of the unequal social structures in Saudi Arabia and because of the lack of formal and informal support for mothers in both countries. Both my Saudi and Bahraini participants faced many obstacles throughout their journeys with autism, though the mothers in Saudi have to contend with significant injustices as I have demonstrated in this study: sex segregation, unequal social status, the guardian laws, and the assumption that a mother's natural role is to assume the burden of care for her family, a burden that women in Bahrain must likewise assume. In Nussbaum's words many women treated as 'mere instruments of the ends of others.' (Nussbaum, 2000, p. 220) To fully understand the barriers Saudi Arabia in particular erected against social justice for women (see Chapter Two), it is fair to say that Nussbaum's view on human entitlements is mostly unheard of, even though, as she argues:

People have some core entitlements just by virtue of their humanity, and that is a basic duty of society to respect and support these entitlements. (Nussbaum, 2011, p. 62)

Many, if not most, women in Saudi are not viewed as fully participating citizens. A life of dignity and respect can only be reached if a woman is lucky enough to come

from a liberal family. In Bahrain, even though women live in a similar society with respect to comparable traditions, women are not controlled by their male guardians and can lead a relatively free independent life if they choose to do so.

Change needs to begin with the family. The structure and practices of families, as Moller Okin argued (1998, p.15), must allow women the same opportunities as men to develop their capacities to be economically as well as physically secure against disadvantage, discrimination and harm, and ignorance of their true potential as human beings. In other words, women, and their children, whatever their disability must be enabled to do to be in ways that reflect who they are, and aspire to be as persons.

7.3 Summary

In this chapter, I analysed the data against Nussbaum's ten central human capabilities and indicated that there are clear disadvantages for Saudi women, merely to be born as women. To live in a country like Saudi Arabia where basic justice for women is ignored, is to live without meaningful freedom of choice and where opportunities are often circumscribed. It is surely abhorrent to give power to a human being over another just because of their sex but such power is demonstrated clearly in the male guardianship law which all Saudi mothers in my study must endure. To enable Saudi women in particular to reach above the threshold level of functioning in all 10 capabilities, and to emphasise their and Bahraini mothers' equal worth, is a moral duty and would be a sign that a society is concerned with some level of social justice. Further work to highlight issues of discrimination and gender inequality is needed in order to establish a life worth of dignity and respect, in which the basic entitlements Nussbaum discussed should be followed and promoted. In the next and the final chapter I will pursue this argument as I conclude my thesis.

Chapter Eight: Conclusions and Reflections

Her soul remained hanging in a place that rejects her bright colours.
 She is tormented by rejection and internal wars the objective of which
 is to draw the boundaries and close the windows.
 Umaima Al-Khamis, cited in Al-Rasheed, 2013, p.175

8.1 Introduction

A socially just society is one with social arrangements which enable all its citizens to do and be in ways that enable them to be the kind of persons they wish to be without barriers or restrictions based on class, race, gender, ability or other non-moral categories.

Unfortunately, as I have shown in this thesis, many women in Saudi Arabia cannot plan a life of their own choosing simply on the grounds that their sex is female. When we add their role as the primary carers for sons with autism to their sex then they are further restricted. In Bahrain, although, as in every country in the world, inequalities and injustices exist, there are many more opportunity freedoms for women to claim their entitlements as citizens and private persons than in Saudi Arabia.

The quote from Umaima Al-Khamis in the epigraph to this chapter could sum up the lives of many of the mothers in my study. Each mother's soul seems to hang in a place, her society and home, in which many of the mothers cannot see her bright colours because she is a woman, and a woman with an autistic child. The women in my study talked of feelings of despair, loneliness and rejection by what I judge to be a sometimes harsh and an unfair society, which stigmatises them and their sons with autism.

In this final chapter, I shall provide a summary of my thesis and return to its framework and the research questions. I shall start with a synthesis of the study, then address the research results and discussion with respect to caring for children with autism and with particular regard to the social support afforded to the mothers in my study. I will then move to discuss the challenges and limitations of the research, areas for further research and the impact and contribution of this thesis. I will discuss, too, the impact that researching and writing the thesis has had on me, personally, as well as with respect to any possible

outcomes that might improve the lives of mothers like those in my study. Finally, I will close the thesis with some concluding reflections.

8.2 To Synthesise

The focus of this thesis was the exploration of the journeys of mothers who have adolescents with autism in Saudi Arabia and Bahrain. I sought to explore the mothers' lived experiences with their sons diagnosed with the Autism Spectrum Disorder (ASD) in two countries which have, in some respects, different cultures, traditions and laws. My focus was both on the lives of the mothers and on the levels of support they received from formal and informal sources. I used an interpretive method to interview 17 mothers, 10 in Saudi Arabia and seven in Bahrain (see Chapter Four). The interviews, which lasted between 40 minutes and three hours⁹⁴, provided me with a privileged opportunity to understand something about the lives of my participants and their experience. As noted, I started with one simple question: 'Tell me about your journey with autism?' and then, by referring to the three main phases, encouraged the mothers to voice their stories. As I explained in Chapter Four, I covered two main themes, autism and social support, and under autism I had three phases: pre-diagnosis, the phase immediately following the diagnosis of autism, and the post diagnosis phase with the following sub-themes under each phase: Mothers' awareness, mothers' effective responses and mothers' behavioural responses. As for mothers' interpretation of their sons' different behaviours, it did not feature in the phase immediately following the diagnosis as, by then, the mothers knew their children had autism.

Throughout, I covered formal and informal support and although I asked questions specifically intended to solicit information about support, the participants' responses often pre-empted these questions. Informal support I defined as that from spouse, family and friends, including neighbours, drivers and nannies. Formal support, I defined as being provided by professionals in schools and hospitals, including societal support such as that

⁹⁴ In my ethical approval application and accompanying documents, including the Plain Language Statement for my participants, I had noted that each interview would be between 60 and 90 minutes. However, when my interviewees wanted to continue talking I encountered an ethical issue in itself. I always indicated that we had talked for 90 minutes and that I had said we would not talk for longer than that but, on each occasion when this occurred, the participants asked if we could continue. To have stopped the interview, the conversation, seemed to me to be both culturally and ethically wrong and this is why some interviews were of three hours duration.

from the Ministry of Social Affairs. In each type of support, informal and formal, I analysed the data under two sub-themes, mothers' affective and mothers' behavioural responses. I ended the interviews with the mothers' views of their sons' futures and what they believed would be an ideal situation, and I will return to these responses later when I suggest possible recommendations based on what might be learned from this study. In the following section I will give an overview of the situation in Saudi Arabia and Bahrain where the study took place.

Saudi Arabia, as I discussed in Chapter Two and referred to throughout the thesis, is a male dominated, sex segregated society, in which mothers are expected to be the primary care takers of their adolescent autistic sons. Religious scholars, 'Ulama'a', continue to preach that women should be excluded from the public sphere, even that a woman's voice is considered shameful 'awra'⁹⁵. A principle known as 'Sadd al-tharai'⁹⁶ aims to prohibit certain actions that could potentially lead to sinful behaviours and is widely used in the Kingdom to gain control over people, most often her female citizens (Al-Rasheed, 2013). For example, and as I discussed in Chapters Two, Five and Six, women are not allowed to drive, although there is no religious text stating that this is forbidden. All practices are monitored and controlled, and rejected when not in strict conformity with Wahhabi interpretations of the Quran, including other Islamic groups such as Sufi⁹⁷ and Shia⁹⁸ (see Chapter Two). Adherence to an arguably narrow interpretation of 'Share'a' law means that those who do not follow it are considered evil, disobedient and enemies of Islam, and in this research the women revealed in their testimonies the extent to which these kinds of restrictions added to the difficulties in caring for their children. Cultural interpretations of Islam place severe limitations on the mothers' opportunity freedoms so, for instance, they often are unable to enrol their sons into schools or meet their teachers to discuss their progress as the data in Chapters Five to Seven indicated. When Saudi mothers lament their husbands' lack of care and attention they do not have a problem with the male

⁹⁵ A word used to refer to things that should not be seen or heard in public, such as women's hair and voices respectively.

⁹⁶ Sadd means to block or to prevent and al-tharai' are behaviours thought to lead to sin and evil.

⁹⁷ An Islamic practice which is built on deep spiritual beliefs and worshipping God through the path of love and devotion.

⁹⁸ Explained in Chapter Four.

guardianship law *per se* (See Chapters Two, and Five-Seven) since it is considered a religious practice, but rather with their husbands' behaviours and attitudes.

A narrow interpretation of Islam has led to practices that promote extreme gender inequalities and discrimination against women, in Saudi Arabia more especially. It is asserted that such practices purify the ways of the Prophet Mohammad⁹⁹ and his companions. To achieve piety, women are moral and religious symbols rather than active and respected members of society. Saudi society is distinguished from the rest of the world by controlling all aspects of their female citizens' lives such as education, work, movement and marriage. These restrictions and expectations come through the findings very clearly: Saudi women lack mobility, the freedom to affiliate (see Chapter Seven), to directly intervene or advocate on their children's behalf, to freely and independently make autonomous decisions about their own and sons' best interests, or to live a life that is financially independent of their husbands or male guardians. I suggest that these kinds of restrictions infantilise women, denying them full status as adult human beings capable of making rational and intelligent decisions. I would argue, too, that the stories of the mothers in this study, with particular respect here to limited capabilities such as, bodily integrity, affiliation and control over one's environment as explained in Chapter Seven, raise issues of justice according to Nussbaum (2011) since capability failure leads to lack of social justice. Nora could not take her son to school and because her husband refuses to support her, she cannot even take her son to hospital in medical emergencies (see Chapter Six). These are the kinds of activities that women in many parts of the world, including in Bahrain, take for granted, unless they lack transport, money, access to services or live with controlling husbands. Mothers, anywhere, will have challenges raising children with autism, but Saudi Arabia, because of the restrictions imposed on women and girls, is a particularly challenging country in which to raise a child with autism.

Rasha, who survives on a low income, could not apply for benefit increases without her husband's presence in the Ministry of Social Affairs (see Chapter Six). Rana

⁹⁹ Peace be upon him.

was not allowed to call her son's school to talk to his teacher about her concerns. Instead, she was forced to write a letter which she had to send with her driver, depending on him to deliver it to the school. Not only do these mothers have to contend with the, often, disabling effects of autism, they must do so in a disabling society which jeopardises their capability development as I discussed in Chapter Seven. Women's capabilities to be and do with respect to affiliating freely with organisations, groups and individuals outside the home are restricted. Their opportunity freedoms for bodily integrity and practical reasoning are also restrained. Their emotions are often dominated by thoughts of a difficult future for their sons, fear for their care, and anxiety for their well-being in their absence. The experiences of the Bahraini mothers were different. While they too have challenges caring for sons with autism, and may have non-supportive husbands, these are not constrained by archaic rules and regulations.

Despite the social reforms that are (slowly) taking place in Saudi Arabia, and the call for modernisation (see Chapter Two), the country's radical laws towards women remain biased and so unable to grant women social justice. Women continue to be treated differently based on their sex with limited access to governmental institutions for example, and lack of freedoms in movement and decision-making. A society that does not treat individuals equally, does not offer equal access to resources and equal opportunities, and which discriminates against its citizens on the basis of gender, race or religion, is surely an unjust society?

The research questions I used to investigate mothers' experiences were developed according to different phases as noted above. In each phase I asked mothers about levels of formal and informal support. I categorised the mothers' responses under the sub-themes of mothers' awareness of autism, affective and behavioural responses, and personal interpretation of their experiences. Detailed presentation of these findings were presented in Chapters Five and Six.

In Chapter Seven, I analysed and interpreted these findings against Nussbaum's (2006, 2011) version of the Capability Approach, and more particularly Nussbaum's ten central capabilities. To date, this is the first research of its kind that I am aware of in Saudi Arabia and Bahrain. There has been, perhaps unsurprisingly, no research that evaluates questions

of social justice and capability development with respect to mothers and their adolescents with autism. In the main, what the findings reveal is that in Saudi Arabia in particular, and primarily because of sex segregation and the prohibition on women's independent mobility, Saudi mothers experience significant capability corrosion. In terms of social justice, these Saudi mothers encounter barriers at almost every level that ensure their capabilities cannot be fully developed, as I discussed in Chapter Seven and as I will discuss further below. Bahraini mothers encounter difficulties, of course, and as I said above. However, in the main, their capability development is less inhibited by the social and political arrangements of their country than in Saudi Arabia. In the next section I will synthesise the research findings.

8.3 Research Results and Discussion

Mothers and Autism

I will summarise in this section the findings from the interviews with regard to mothers' lived experiences with autism in both Saudi Arabia and Bahrain which I explained in detail in Chapter Five. Mothers in both Saudi Arabia and Bahrain had similar experiences with autism perhaps because autism is a global disorder that does not differentiate between cultures and manifests similar symptoms in all societies (Mandy et al., 2013). Such manifestations of autism were clear. All 17 mothers noticed their sons' 'different' behaviours such as sleeping disorders and lack of communication, even before they received the official diagnosis. Negative feelings such as confusion and loneliness were experienced by all during this phase. The mothers in my study simply did not know what was happening to their sons except Nada (Saudi) who was working in an Autism Centre at that time and who immediately linked her son's behaviour to autism. Nevertheless, she too experienced feelings of fear and denial because she did not want to believe that her son actually had autism. Because of the confusion caused by their sons' 'strange' behaviour, the mothers tried to make sense of it by attributing the behaviour to, for example, hearing problems or speech delays. Two mothers Rasha (Saudi) and Warda (Bahrain) went as far as linking it to the possession of evil spirits. Nonetheless, and in addition to Nada, three mothers, Maha, Sana'a and Nouf in Bahrain, were able to link their sons' behaviour to autism from internet research. During the mothers' journeys to seek help, five mothers in Saudi (Huda, Sarah, Amal, Mai and Nora) and four Bahraini mothers (Maha, Sana'a, Noor and Warda) received the wrong diagnosis. The misdiagnoses ranged between ADHD, Separation Anxiety Disorder, intellectual disabilities, and some doctors even accused three

Bahraini mothers (Sana'a, Nouf and Maha) of imagining things, saying that their sons were perfectly fine.

After the mothers finally received their sons' official diagnosis they all experienced negative feelings such as hopelessness and sadness, except for Asma'a, Maha and Sana'a (Bahrain) and Sarah, Mai and Nada (Saudi) who felt relieved because they could name their son's condition and take action to care for them appropriately. The mothers dealt with the autism in different ways. A common behaviour, though, with mothers in both countries (Huda, Sarah, Amal, Rana and Noha from Saudi; Asma'a, Samia, Noor, Warda and Nouf from Bahrain), was that they started to educate themselves about autism by reading books and surfing the web. Sarah and Rana from Saudi; and Asma'a and Noor from Bahrain started attending lectures and workshops, with Rana, volunteering in an Autism Centre to gain first-hand experience. Twelve mothers (Huda, Nora, Amal, Noha, Mai, Rana, Rasha and Nada from Saudi; Noor, Nouf, Asma'a and Sana'a from Bahrain) used other methods to try to help their sons from an autism diet to Imams to citing the Quran.

Once their sons reached the adolescence phase, some boys showed changes in their behaviours while others did not. According to their mothers (Rana, Sarah, Noha and Nada from Saudi; Asma'a, Samia, Warda and Nouf from Bahrain) eight boys showed inappropriate sexual behaviour such as touching themselves and others in sensitive areas. One boy in Bahrain had wet dreams (Sana'a) and another masturbated (Nouf). Seven of the boys (Fatima, Huda, Sarah, Nada, Amal and Rana from Saudi; Samia from Bahrain) showed changes in personality such as stubbornness, breaking the rules and becoming more sensitive to others' comments. Three boys in Bahrain (Maha, Asma'a and Samia) developed epilepsy.

Mothers' experienced different affective responses during this phase in their adolescents' life that ranged from accepting those changes as normal and natural, to feeling confusion, helplessness, fear and embarrassment. Regardless of their sons' age, eight mothers from both countries (Nora, Fatima, Rasha, Amal and Mai from Saudi; Asma'a, Sana'a and Nouf from Bahrain) still help their sons shower and shave, while five (Huda and Noha from Saudi; Asma'a, Sana'a and Nouf from Bahrain) tried to teach them how to be independent.

Dealing with sexual arousal, mothers responses ranged from talking about sex, praying or giving the adolescent space to masturbate in private.

Mothers and Social Support

In this section, I will summarise the findings from the interviews about mothers' lived experiences with social support informal and formal in both Saudi Arabia and Bahrain which I explained in details in Chapter Six.

Informal Support

I will first discuss informal support noting that living with a supportive husband is likely to have a positive impact on the mother's well-being (see Brobst et al., 2009). Saudi mothers have a different experience with their husbands compared to Bahraini mothers because of the male guardianship law (see Chapter Two) as, in Bahrain, husbands as male guardians do not have unlimited power and control over their wives. While mothers in both countries experience negative support from their husbands, the Saudi mothers' experiences were more difficult. Some husbands were completely withdrawn from their sons' lives, some were controlling and yet others did not visit their sons' schools. Three mothers (Fatima and Nora from Saudi; Maha from Bahrain) lack financial support from their husbands, and the husbands of three blame them for the disorder (Amal and Rana from Saudi; Maha from Bahrain). Two Saudi mothers, Fatima and Nora, live with abusive husbands Mothers who experienced negative support from their husbands felt lonely, hurt and depressed, while those who received positive support showed their happiness and gratitude. In the case of four Saudi mothers (Amal, Rasha, Rana and Nada), they tried to find excuses for their husbands' behaviour by attributing it to the nature of Saudi men, while three mothers understood their husbands' limitations (Rasha and Nada from Saudi; Noor from Bahrain). Sarah (Saudi) is pleased her husband is not involved in his son's life since she does not want him to be like his father. Four mothers in Bahrain have their husbands' full support (Asma'a, Samia, Noor and Nouf), while four husbands in Saudi Arabia show occasional care towards their wives (Sarah, Rana, Noha and Mai). Three husbands in Bahrain take part in the direct physical care of their sons (Asma'a, Sana'a and Nouf). In Huda's case (Saudi), she has a very supportive husband who has a good relationship with his son and is involved with his care.

Mothers also received informal support from friends, families and neighbours. Eleven mothers had supportive children who were willing to help with their brothers (Huda, Nora, Sarah, Noha, Nada, Mai and Rana from Saudi; Asma'a, Sana'a, Noor and Warda from Bahrain). Five mothers in Bahrain have supportive families (Asma'a, Sana'a, Samia, Noor and Maha), while two do not (Warda and Nouf), while three mothers from Saudi lack any kind of family support (Amal, Mai and Rana).

Formal Support

Under formal support, I addressed the support of hospitals, Autism Centres and societal support, and I will start with summarising the mothers' view of the support they received from hospitals. Most mothers reported negative experiences with the hospitals. Ten mothers failed to obtain a diagnosis (Nora, Rasha, Amal, Nada and Rana from Saudi; Sana'a, Noor, Maha, Warda and Nouf from Bahrain). Eight mothers thought the hospital did not provide enough care or information about the disorder (Rasha, Fatima, Noha, Rana and Nora from Saudi; Nouf, Noor and Warda from Bahrain). Hospitals failed Nora repeatedly.

In terms of schools and Autism Centres, nine mothers reported the schools' lack of care (Fatima, Huda, Rasha, Nada, Mai and Rana from Saudi; Asma'a, Samia and Warda from Bahrain). Yet eight mothers reported a good improvement in their sons' behaviour because of the school (Huda, Sarah, Mai and Rana from Saudi; Asma'a, Maha, Warda and Nouf from Bahrain). Four mothers (Noha and Nada from Saudi; Warda and Maha from Bahrain) educated their sons abroad. In some cases, the lack of financial means prevented the mothers from enrolling their sons in specialised Autism Centres, of which there are very few (Fatima, Nora and Raha from Saudi). One mother (Samia) moved from Saudi Arabia to Bahrain to get her son into school, and to have freedom of movement and access to social, recreational and health services. Two issues that only Saudi mothers had to encounter were male guardianship and the sex segregated educational system, as explained in Chapters Two and Six. As I explained in these chapters, a Saudi mother needs written consent from the father to ensure the son's acceptance in school. Mothers can rarely contact the schools directly which means that if any difficulties arise, either they must rely on their husbands' willingness to get involved or the schools' willingness to talk to them.

The Ministry of Social Affairs in Saudi Arabia is responsible for individuals with disability and they issue a disability card which parents use to obtain benefits and other services (see Chapter Six). Like all institutions in Saudi Arabia, they follow the male guardianship law, which in this case means that mothers cannot obtain a new card or renew an old one without the presence of their husbands. If the husbands refuse, there is nothing the mother can do and she must go without the benefits, as learned in the cases of Rasha and Nora.

Another form of formal support is societal support which includes social awareness, how others' react to autism and the availability of social networks. Five mothers believe there is not enough awareness about autism (Noha, Nada, Amal and Mai from Saudi; Nouf from Bahrain), while for five mothers the awareness of autism is increasing (Rana from Saudi; Samia, Noor, Maha and Warda from Bahrain). A few mothers were subjected to humiliating remarks and looks because of their sons' different behaviour, Amal (Saudi) and Asma'a and Sana'a (Bahrain) (see Chapter Six). Being divorced is also difficult as Maha (Bahrain) attested.

In terms of social networks, my data indicate a significant and important difference between Saudi and Bahrain. Since Bahrain is a smaller country and people are more accepting of others' differences compared to Saudi Arabia, it is easier to spread awareness of autism and form social networks. Asma'a and Warda are founders of awareness committee and parents' association for children with disabilities. Such supportive circles do not exist in Saudi Arabia, perhaps due to the size of the country, perhaps due to a lack of cultural familiarity with such networks, perhaps due to gendered assumptions and restrictions, and perhaps, due to the warm friendly nature of Bahraini people which I have personally experienced.

The Stories of Mothers and the Capability Approach

As noted above, I used Nussbaum's CA and her ten central capabilities to examine mothers' positions in both Saudi Arabia and Bahrain. I looked at the impact of the lack of capabilities on mothers' ability to provide support for their adolescents with autism, and to explore the social arrangements of the societies in which they live. While discussing the data I did not follow Nussbaum's order of the 10 capabilities, but rearranged them

according to the most dominant ones with respect to the Saudi mothers given the special structure of Saudi society. Like Nussbaum (1999, p.57) I would argue that all mothers, ‘just by being human, are of equal dignity and worth’. Relatedly, all mothers in my study deserve a life worthy of dignity and respect. Unfortunately, with the humiliating rules and regulations, and the added demands on them as primary carers of autistic sons, it seems to me that they are merely pawns controlled by their society.

I started the discussion by applying Capability 3, Bodily Integrity (see Chapter Seven), since every Saudi mother was unable to move freely from place to place, unlike the Bahraini mothers who are allowed to drive, and so have freedom of mobility. Saudi mothers like Rasha, for example, do not have the financial ability to hire a driver and has to be dependent on her husband or her sons to gain mobility, one of the reasons she could not send her son to an Autism Centre (see Chapter Six). As for security against violent assault, two Saudi mothers (Fatima and Nora) were physically abused by their husbands, though Fatima managed to get a divorce while Nora had to live with her abusive husband. Also, Nora and both her daughters were verbally-sexually assaulted by the driver who still drives Nora’s daughters to university because she basically has no choice and does not want their education to end through lack of transportation (see Chapter Seven). Rana, Nora and Amal lack sexual satisfaction yet they are still with their husbands, either from lack of alternatives, feelings of duty, or feeling sorry for them, as Amal said:

I feel sorry for him especially in his age, what would he do? Where would he go? He is a man with no interest, no hobbies, he stays home all day long watching TV, drinking his coffee and goes to bed early. (Amal, SA).

With respect to Capability 7, Affiliation, mothers in both countries had the ability to show concern and recognition toward their sons and other mothers of children with autism. As for social interaction, mothers mostly lived in isolation because of their sons’ autism symptoms unless they are interacting with other mothers going through similar experiences. Many mothers were humiliated because of the humiliation their sons experienced from lack of social awareness about autism. Mothers were also discriminated against because of their sons’ condition and in Saudi because of their gender. The next capability that is significantly compromised in Saudi Arabia is Capability 10, Lack of Control over One’s Environment, something mothers in both countries struggled with

because of the characteristics of autism. However, it was far worse for mothers in Saudi because of laws such as male guardianship and sex segregation (as explained in Chapter Two). Saudi mothers fall under gender discrimination and unfair practices which they have no choice but to endure. With respect to Capability 4, Senses and Imagination, mothers in both countries had the ability to imagine their sons' future. Yet this had a negative impact on them due to the lack of options available for their sons which result in feelings of fear and anxieties. As for Capability 5, Emotions, all mothers had the ability to love their sons and feel attached to them, though their lives were affected by fear, despair, concern and stress. As for Capability 6, Practical Reasoning, mothers did not have the ability to plan their lives apart from their sons since they are the ones providing care; neither are they free to plan a life according to their wishes since, in Saudi Arabia, they need the consent of their male guardians. In terms of Other Species, Capability 8, only two mothers have adolescents who are attached to animals and planting. With Capability 9, Play, mothers struggled with the crushing burdens of their sons with autism which left them no time for fun or enjoyment. Overall, most of the participants failed to reach threshold levels of functioning in a number of Capabilities, impacting on their respect and sense of dignity.

Rasha (Saudi), used the word '*forgotten*' and said that mothers of individuals with autism are on their own without any help or support and, since breast cancer runs in her family, she is worried something might happen to her meaning that Sami will be left alone with no one to care for him. Mai (Saudi) wondered if having autism means '*the end of the world*' since Rami has to remain at home and she cannot find an Autism Centre for him. Yet another issue Mai suffer is nationality as being a Jordanian in Saudi Arabia does not allow Rami to participate in many activities with the banner 'for Saudis only' often used. Although Samia is a Lebanese mother living in Bahrain, she does not seem to be facing this issue. On the contrary she calls Bahrain home and she jokes with her husband saying '*If I die, bury me in Bahrain, do not take me back to Lebanon*'. Mothers' fears and desires were clearly demonstrated during the interviews, and in their answers to my last question as I addressed in Chapter Six, and will summarise in the next section.

The Future

I ended the interviews by asking mothers about their fears, desires and what they believe is the ideal situation for their sons. All mothers were fearful for their sons' futures and hoped

they would not die before their sons did (Huda and Warda, for example). Among the things they desired were good Autism Centres in order to, for example, bring their sons back from abroad (Maha, Bahrain), or to see their sons. Noor (Bahrain) had a vision of a brighter future seeing Waleed as a writer, having a supportive husband and a supportive family. Warda (Bahrain) wished only for physical strength to continue providing care for Taher, Nouf (Bahrain) wanted Sultan to be happy gardening and to be able to support himself. Sarah (Saudi) like Noor, was optimistic about Maher's future seeing him as a creative architect. Amal (Saudi), though, expressed her agony at the question, and revealed her wish to leave her husband whom she described as an obstacle to her own and Kareem's well-being. She believed Kareem had an undiscovered talent, seeing him, like Noor does of her son, as a writer. As for Rana (Saudi) a mother of Yazeed and Zaid, two adolescents on the spectrum saying that her sons will not develop or progress if they stay in Saudi Arabia. She also shared that her oldest daughter is planning to apply for a scholarship to study medicine abroad, and if she succeeds Rana and the boys will accompany her to find them a better future.

8.4 Challenges and Limitations of the Research

Here, I will discuss both the limitations and the challenges of the study in this section, because some of the challenges I encountered are also limitations of the research. The findings of this research provide a glimpse into the lives of some mothers of adolescents with autism and indicate the dilemma of autism, a lack of services, the poor support and an unjust society. Before I started collecting data, I had some idea about the mothers' situations in both countries because of my Masters degree, and because I am from Saudi Arabia, and live and work in Bahrain. Although I had collected data from Saudi Arabia for my previous research, I did not meet mothers but used questionnaires to collect information about their adolescents' sexual behaviour, as I explained in Chapter One. I knew the issues of Saudi women in society such as the male guardianship law and sex segregation and its effect on their capacities to provide care for their sons, but I was not prepared for the amount of suffering and agony they shared with me. Their stories reported abuse, humiliation, grief, depression, sorrow and heartache. To meet the mothers, to listen to their stories and to feel their pain was, at times, overwhelming for me as a researcher, as I explained in Chapter One and Chapter Four. The data collection was a stressful procedure and the stress continued throughout the research as listening to the recordings, translating

and transcribing were both emotionally and physically exhausting. Because of the struggles mothers had shared with me, I felt drained every time I listened to or read the data and I can still picture the participants' faces, their emotions and their crushing burdens (Swift et al., 2009). Yet, mothers were desperate to share their stories with me; it was a release. I was talking to Nouf when she started crying. Between her tears and my apologies for bringing up such memories, she said:

Thank you for talking to me, I don't remember when did I last talked about my struggle, perhaps Allah (God) sent you to me so I can let out all that in my heart. (Nouf, B)

There were similar reactions from all of the participants. They all wanted to talk and share their stories and issues. When I first called Noha (Saudi) and introduced myself and my research, giving her the option of meeting me or talking on the 'phone, she said: *'No, no! This topic needs us to meet and talk. Such a big issue cannot be discussed over the 'phone'*. Noha felt the need to meet me in person to express her struggles with the services and support and kept repeating that no one cared for her sons, and that they were completely neglected and ignored. Even though I interviewed other mothers over the 'phone (see Chapter Four), their emotional distress was still obvious. As I explained in Chapters One and Four, to control my emotional reactions in front of the mothers was not easy, and I felt obliged to provide more transcripts to let their voices be heard. However, and because of the limited number of words allowed I have provided more of their stories in Appendix One. It was hard not to relate personally to the mothers I interviewed. Although subjectivity can affect objectivity in the academic research (Ratner, 2002), I argue that if it were not for the personal connection and self-reflection, I would have not been able to address the participants' issues fairly. The distress I felt was in response to their plight. To feel strongly about a cause, to have passion and the emotional connection I formed with my participants, pushed me to work harder to bring their voices to life.

As I read the transcripts and went back to the recordings, I sometimes wished I had the opportunity for follow up interviews but, due to time-limitations (mine and the mothers'), unfortunately, this was not possible and this lack of follow-up is one of the limitations of my study. If I have managed to meet the mothers again, perhaps, they would share more experiences they could not share the first time. As I noted in Chapter Four, not because certain issues were shared by few mothers, it means the rest did not experience the same issues, and if follow up interviews were possible, they might share similar issues. I do not claim that my results are generalisable beyond my participants and so this, too, is in some

respects a limitation. However, this research is, I believe, an important way to start conveying what mothers are experiencing in their care of autistic children, including Saudi mothers living in a highly rigid and controlled society. The interviews raised issues of mothers' well-being, their lack of supportive environments, and their needs. Their responses showed that their perceptions of their future well-being were dependent on the availability of services and support needed by their sons, such as good Autism Centres and qualified professionals. In addition, and specifically in Saudi Arabia, the ability to provide care without being utterly constrained by the male guardianship law with respect to enrolling their sons in school and applying for a disability card, for example, is critical, not only to the mothers' well-being, but also their sons. This raises issues of justice, in which having the ability to care for your son depends on someone else's permission, if not benevolence.

Another challenge and perhaps a limitation I faced during this research was the translation of the interviews. In addition to the fact that it was a time-consuming process, I was also anxious not to lose any of the mothers' thoughts, especially given that language is:

Largely culture oriented and therefore, translators face the problem of translating certain culture based words into another language with a different culture. (Ray, 2008, p.48)

The participants often used cultural expressions with no equivalent in the English language and so I had to find a way to translate them without jeopardising the meaning. Another related issue I had to deal with was cutting the data and yet to do justice to the voices of my participants. As I explained in Chapter Four, I had a huge amount of data. The interviews varied in length but some of the transcribed notes and extracts ran to 5000 words. There is a maximum word length for a PhD thesis, it has to be written in temperate academic language and it requires more than simply giving voice to hitherto unheard participants. This meant I struggled between the desire to share the full stories of the mothers and the number of words I could use alongside the analysis and interpretation needed in each chapter.

I felt duty bound to tell the mothers' stories because their stories are unique, each mother has her own struggle to share. I was also very aware of the time they had given me despite their heavy schedules. Some mothers met me with their sons and I witnessed their suffering as the only person who provides care. Although they had no obligation towards me, they chose to sit and

share their stories. To cut short the data felt like an act of injustice, as if I were breaking their trust in me to have their voices heard. It sometimes felt as if I, too, as in the epigraph to this thesis, was ‘hanging her soul in a place that rejects her bright colours’ and drawing the boundaries and closing the windows’. In some ways there are eighteen stories in this thesis: 17 from the mothers who generously talked to me and one from me, as a researcher and a human being.

During the research, I tried to reach out to mothers who had daughters with autism but failed to do so, another limitation of his study. Although I managed to contact some mothers, they were unwilling to discuss the adolescence issues with me. I faced a similar issue during my previous research when Saudi mothers claimed their daughters on the spectrum did not engage in any sexual behaviour because they were girls. Another reason for the difficulty, beside gender-sensitivity, is that more boys than girls have autism (see Chapter Three), though there is increasing research to show that girls may be under-diagnosed (Andersson et al., 2013).

Another limitation is that my thesis focusses only on the mothers of children with autism and not on those children themselves. To have talked to the adolescents being cared for by the mothers in my study would have given them a voice and provided fascinating data but, in one PhD, it was not possible to do this and so, inevitably I think, I had to make a choice. Some of these limitations might form an agenda for future work and I now turn to this.

8.5 Future Work

This research was about mothers’ lived experiences with respect to autism and support and it relies heavily on verbatim extracts and summaries of their words. It tries to give voice to their own perspectives. To investigate the same topic from a different perspective may also be important. To take into consideration fathers’ point of views, for example, or those of professionals, might add value to the topic in question and shed more light on the reality of support and the autism disorder. Another important and underdeveloped research area is to investigate mothers who have daughters with autism, as I noted above. In Saudi Arabia, sex segregation will not present any difficulty since mothers can visit their daughters’

schools. There may be questions of social justice that are being overlooked by not addressing the needs of girls with autism.

Another important area to research is with regard to policies in respect of the rights and, in the language of the CA, the entitlements, of individuals with autism and other disabilities in both Saudi Arabia and Bahrain. The role of official institutes like the Ministry of Health and the Ministry of Social Affair, their available services for the individuals with disabilities and their families, could make a valuable contribution to the research. On a bigger scale, research might be required to investigate more participants from different cities in Saudi Arabia, taking into consideration the cultural differences between cities such as Riyadh, for example, which is more conservative than Jeddah.

8.6 Impact and Contribution of the Thesis

I was raised in a middle-class family which valued education, and I was blessed with an amazing father who never used the power of male guardianship, a law I only knew existed by hearing about other peoples' experiences. A high school English teacher taught me kindness and justice, and if it were not for his teaching, which defied an unfair society, I would not be who I am today, and this work would not have been undertaken. The teacher pushed me towards an education in a society that pushes the girls towards marriage, and I was allowed to choose my own path when other girls were forced to follow what their fathers chose for them.

With respect to the contribution this thesis might make to the field, it is, as far as I know, the first to collect, analyse and interpret data from mothers of adolescents with autism in Saudi Arabia and Bahrain using qualitative research and interviews. I suggest that more such research is needed if we are to better understand autism, disability and its effects and if we are to be in a position to hope for change. Additionally, and as I explained in Chapter Four, in the 'good research' section, a positivist approach with quantitative, often statistical hypothesis-testing research, is what is most frequently used to conduct research back in Saudi and Bahrain. Thus to do research that entirely depends on conversations with the participants, in which they share their stories, is not common and this, in itself, is a contribution to the field in my geographical context. Until more such research is

undertaken then the collection of such rich data will remain unusual or, at worst, judged not to be ‘proper research’.

I have not come across a study in either Saudi or Bahrain that emphasises ‘giving voice’ to often unheard participants in a way that encourages and allows them to express their emotions about autism and their societies by using their lived experience as the basis for the research. My deployment of Nussbaum’s Capability Approach in this field and in this context is also, I believe unusual if not unique and goes a small way, I hope, to showing how this approach can be applied in such research with particular respect to issues of social justice and the flourishing of all, and I refer to this again later in this Chapter.

An important aspect of doing research is to improve others’ situation by developing social practices (Kemmis & McTaggart, 1988), which I hoped to do by understanding the struggles of the participants and their needs as a small step towards improving available support for them and their adolescents with autism. My thesis aims to contribute to improving the situations of mothers like my participants by attempting to understand the societies they live in, the services and support available for them, and their adolescents with autism from their own perspectives. The study is an attempt, further, to give such mothers a voice. Thus, during the journey of this research, I learned not only about how women live in my birthplace, but also about myself. What I thought would simply be ‘a description of someone else’s experience’ changed and touched me on a personal level, as I intimated above. Things which I believed were direct and simple, such as enrolling children with disability in boarding schools, or performing sterilisation procedures on girls with autism and other disabilities, as one of my participants said she will do to her daughter who has an intellectual disability, turned out to be complex and difficult. I thought a mother who wished for her son’s death to free herself from his responsibility was selfish, and merely a martyr of unfair circumstances.

This folding back on oneself is problematic and yet without it we, as researchers, have not accounted for the element of ‘self’ within the research. Each researcher has a moral duty to look within and communicate publicly what is there. (Ryan, 2005, p. 3)

As Ryan stated in the quote above, the folding back was not easy to recognise or to discuss. To form a personal link with other people’s experiences, and change one’s convictions is

hard, yet important. I changed my mind when I interviewed my first mother, Fatima, who has three children with disabilities, visual impairment, intellectual disability, and autism. I was speechless. An illiterate woman who is trying to make a living and take care of her children working as a cleaning lady in the girls' college on a minimum wage made me angry and sad. I was sad for her and angry at society, angry at the lack of help and support, and angry at the system. That first experience moved me, yet did not prepare me for the rest of the interviews. As I went on, I met with more suffering and struggles. Even the mother who worked as a high-ranking state employee, who, one would think, is living a relatively stress-free life, had lost a son and had to live with an unsympathetic husband who had completely withdrawn from her life (see Chapter Six).

Mothers I interviewed showed me that people have a voice only if we are willing to listen, and are prepared to help in whatever ways we can. I experienced emotions of guilt, as I discussed in Chapter One, as I engaged the participants in mostly gloomy conversations without being able to offer any solutions for their agony. I felt as if I was using their suffering for my own personal agenda to collect research data, to gain a PhD, without helping them. Yet, listening to their stories in person, and through the recorded data many times, allowed me to deeply understand their lives. This work, if read by teachers in the general education system, could offer an insight into the lives of individuals with autism and their mothers, especially with regard to autistic students who attend the state schools. A better understanding of autism and the needs of both those with autism and of those who care for them might help the integration process within society and eventually lead to inclusion. Also, such understanding may help to avoid the stereotyping of autism, and help prevent bullying, an issue that a number of mothers in my study reported (see Chapter Six). As noted in Chapter Three, autists find it difficult to recognise and respond to the needs and norms of many social settings and this makes them socially vulnerable and they become easy targets for bullying (Szalavitz, 2002). Therefore, to raise awareness of bullying, but of autism more generally, is critical. Teachers ought, and I think many want, to create a safe environment for all children and young people and that means teaching respect and, also, teaching about those who, like the boys talked of by their mothers in this study, are 'different'. Similarly teachers need support to recognise the signs of exclusion, stigmatization and bullying and teacher education and continuing professional development has an important role to play here. Almost all of my mothers talked of societal prejudices and a lack of understanding with respect to autism. And I can only hope

that this study makes a small contribution to changing attitudes following the social model that requires society, not the disabled individual, to change through improved education for teachers. In turn, teachers could work with their pupils and students and, in time, society might not be so negative or lacking in understanding.

As for the Capability Approach, as far as I know and as stated above, no other study has used Nussbaum's CA to address and evaluate the lives of mothers of children with autism. Moreover, I have not found other studies using the CA to consider issues of justice in a way that connects these to the lives of women, the mothers of autistic adolescents, autism, support and traditions. To focus on the well-being of individuals, arguing that every person is entitled to a life of dignity and respect, and that society must enable everyone to have at least a threshold level of functioning in the ten central human capabilities, are all concepts and arguments that, to my knowledge are unfamiliar if not unheard of currently, in both Saudi and Bahrain. This, then, a study using the CA and focussing on the lives of mothers of children with autism in the particular contexts of Saudi and Bahrain is a further contribution. I hope the study might ignite an interest in both Nussbaum's CA and such research explorations that, as noted earlier in this Chapter seek to give voice to and to better understand people's lives. Finally, with respect to the possible contributions this thesis makes, one of the criticisms against the CA (see Chapter One) is that it is too general and does not relate to particular contexts. In this study, I have shown how this criticism is not necessarily justified by applying the list specifically according to the culture of Saudi and Bahrain in which my mothers are located.

In Chapter Seven, I used Nussbaum's approach of the ten central human capabilities and related them to the mothers' stories. I started with the capabilities that feature the most in the mothers' struggle and bodily integrity: being able to move freely from place to place; to be secure against violent assault, was the first to be addressed then I moved to Affiliation (See Chapter Seven). I hope that by discussing the data around the notion of social justice, mothers' well-being, discrimination and inequality, I would be able to offer a new way seeing these women's lives and to ask questions about the urgent need for change within the society. Perhaps through publication of parts of this work in international journals, I might be able to bring this to the attention of key stakeholders, such as policy makers, official institutes including the ministries responsible for individuals with disabilities, and Autism Centres and schools. Perhaps the data could be shared, in a different form, with

mothers who are experiencing similar issues so they might know they are not suffering alone. Perhaps, too, such data could be shared by their husbands and families so they develop a better understanding of the mothers' feelings and what they are going through. Surely, only by considering the emotional and the social aspects of mothers' lives, will we be able to provide the essential support needed, and if functioning can be achieved beyond a threshold level in most of the capabilities, we could achieve better possibilities for the mothers and their sons.

8.7 Towards the End

This study sought to offer a better understanding of the lives and experiences of mothers of adolescents with autism in both Saudi Arabia and Bahrain. These are two similar countries yet they are very different. They share the same language, the same location, and, mostly, the same religion and yet many unjust laws and customs do not prevail in Bahrain. These include the humiliating rule of male guardianship, which gives society's male members full control over women just because of their sex, in addition to a sex-segregated system which prevents mothers from doing things as simple as having access to their sons' school. Unfortunately, with such unfair rules and regulations embedded in the social fabric and a resistance to change, a different society cannot be expected any time soon. Reform will be slow for 'any change in gender relation and the role of women is considered a form of interference in God's plan for the universe and Saudi Arabia's special commitment to Islam' (Al-Rasheed, 2013, p.256).

Although I acknowledge the limitations and the challenges of my work, it matters that I was privileged to talk to and communicate with the mothers who put their trust in me, and I know that many of their stories will remain with me forever. Only by identifying their troubles and suffering, can we come to a better understanding of their needs and be able to inspire change and make a difference. The title of my study is: 'Journeys of Mothers of Adolescents with Autism in Bahrain and Saudi Arabia: Issues of Justice?'. My final answer is, 'Yes, these journeys raise issues of justice'. Situated in Bahrain and Saudi Arabia the study also raised issues of respect and dignity for carers but, so too, for those with autism and, by implication at least, for all with disabilities and impairments. Writing over a decade ago, Nussbaum (2009) argued that 'doing justice to people with physical and mental

impairments' (p.1) was an unsolved problem of social justice that would require 'a new way of thinking about who the citizen is' (p.2). That new way of thinking would need, stated Nussbaum (2009, p.2), an emphasis 'on the importance of care as a social primary good' and it would need 'imaginative courage' (p.415) to meet the challenge. The title of my thesis raised a question of justice, and by the end of my work, mothers are indeed facing issues of justice. There is far to go and much work to be done before we are likely to see significant changes and this thesis is but a small step on a long journey that will take both courage and imagination if the lives of the mothers in my study, and the lives of their children, are to be better.

References

- Aart, P., Meijer, R., Wagemakers, J., Kanie, M., & Glee, A. V. (2012) Saudi Arabia between Conservatism, Accommodation and Reform. *Netherlands Institute of International Relations 'Clingendael'*, 7. Retrieved (01/ 2014) from: https://www.clingendael.nl/sites/default/files/20120000_research_report_rmeijer.pdf
- Al-‘Arniri, S. M. (2001) The Birth of Al-Wahabi Movement and Its Historic Roots. *The General Military Intelligence Directorate, Presidency Headquarters*. Republic of Iraq. Retrieved (01/ 2015) from: <https://fas.org/irp/eprint/iraqi/wahhabi.pdf>
- Alan, H. & Lauren, S. (2008) Autism's Challenges: Combating Stress on the Home Front. *The Exceptional Parent Magazine*, 38(4). Retrieved (02/ 2014) from: <https://www.questia.com/magazine/1G1-178220239/autism-s-challenges-combating-stress-on-the-home-front>
- Al-Dakhil, K. (2007) *The Rise of the Wahhabi Movement and the Saudi State*. Washington Post Foreign Service. Retrieved (04/2014) from: <http://www.washingtonpost.com/wpdyn/content/discussion/2007/02/01/DI2007020101782.html>
- Al-Farsy, F. (2009) *Modernity and Tradition: The Saudi Equation*. New York: Routledge Publisher.
- Al-Gharaibeh, F. (2011) Women’s Empowerment in Bahrain. *Journal of International Women’s Studies*, 12(3), 96-113.
- Al-Hibri, A. (1997) Islam, Law and Custom: Redefining Muslim Women's Rights. *American University International Law Review*, 12(1), 1-44.
- Al-Jadid, MS. (2013) Disability in Saudi Arabia. *Saudi Medical Journal*, 34(5), 453-460.
- Al-Jishi, B. J. (2013) Reforms and Political Participation of Women in the Kingdom of Bahrain. *Turkish Policy Quarterly*, 11(4). Retrieved (06/2014) from: <http://turkishpolicy.com/Files/ArticlePDF/reforms-and-political-participation-of-women-in-the-kingdom-of-bahrain-winter-2013-en.pdf>
- Al-khateeb, S. (2007) *The Oil Boom and Its Impact on Women and Families in Saudi Arabia*. London: SAQI publishing in association with London Middle East Institution SOAS.
- Alnemary, F. M., Aldhalaan, H. M., Simon-Cereijido, G. & Alnemary, F. M. (2016) Services for Children with Autism in the Kingdom of Saudi Arabia. *Autism*, 1-11.

- Al-Obaidli, M. (2012) Women's Empowerment in Bahrain: The Interplay between Government Policy and Globalization. *The third Gulf Research Meeting (GRM). University of Cambridge*. Retrieved (01/ 2015) from:
http://gulfresearchmeeting.net/common/pdf/FM_GRM_2012-web.pdf
- Alqahtani, A. (2014) Evaluation of King Abdullah Scholarship Program. *Journal of Education and Practice*, 5(15), 33-42.
- Alqahtani, M. (2012) Understanding Autism in Saudi Arabia: A Qualitative Analysis of the Community and Cultural Context: Understanding autism in Saudi Arabia: A Qualitative Analysis of the Community and Cultural Context. *Journal of Paediatric Neurology*, 10(1), 15-22.
- Al-Rasheed, M. (2013) *A Most Masculine State. Gender, Politics, and Religion in Saudi Arabia*. : London: Cambridge University Press.
- Al-Rayes, R. (2012) Family Law in the Kingdom of Bahrain. *Zeenat Al-Mansoori & Association*. Retrieved (10/2015) from:
http://www.zeenatalmansoori.com/articles/ARTICLE-Bahrain_Family_Law.pdf
- Al-Sharif, M. (2012) Driving My Own Destiny Defying the Ban on Female Drivers in Saudi Arabia. *Virginia Quarterly Review*, 88(4), 96-101.
- Alturki, N. & Braswell, R. (2010) *Businesswomen in Saudi Arabia: Characteristics, Challenges, and Aspirations in a Regional Context*. Retrieved (08/ 2014) from:
<http://www.jeg.org.sa/businesswomen.pdf>
- Al-zaalah, M., Al-asmari, A., Al-malki, H., Al-shehri, N., Al-moalwi, N. & Mostafa, O. (2015) Characteristics of Autism Spectrum Disorder among Saudi Children and its Impact on their Families. *Medical Journal of Cairo University*, 83(2), 239-244.
- Anderson, G. & Arsenault, N. (2002) *Fundamentals of Educational Research*. London: Routledge Falmer.
- Anderson, G. L. (2009) *Unintentional Humour: Celebrating the Literal Mind*. Massachusetts: Gund publisher.
- Andersson, G., Gillberg, C., & Miniscalco, C. (2013) Pre-school Children with Suspected Autism Spectrum Disorders: Do Girls and Boys Have the Same Profiles? *Research in Developmental Disabilities*, 34, 413-422.
- Anjali J., A., Marshall, J., Buikema, A., Bancroft, T., Kelly, J. P. & Newschaffer, C. (2015) Autism Occurrence by MMR Vaccine Status Among US Children with Older Siblings with and Without Autism. *Journal of the American Medical Association (JAMA)*, 313(15), 1534-1540.

- Bahkali, W. A. (2011) *The Issues of Work Life Balance for Saudi Women Workers*. Unpublished master's dissertation, University of Waikato, New Zealand. Retrieved (03/2015) from: ProQuest Dissertation and Thesis Database.
- Bahrain Factsheets (2013) *Women- Living and Working in Bahrain*. Retrieved (07/2015) from: <http://www.bahrainedb.com/en/EDBDocuments/EDB-Women-in-Bahrain-May-2013.pdf>
- Bailey, D. B., Skinner, D., Correa, V., Arcia, E., Reyes-Blanes, M. E., Rodriquez, P., et al. (1999) Needs and Supports Reported by Latino Families of Young Children with Developmental Disabilities. *American Journal of Mental Retardation*, 104(5), 437-451.
- Baio, J. (2014) *Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010*. Centres for disease Control and Prevention. Retrieved (10/ 2015) from: http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s_cid=ss6302a1_w
- Baker, J. (2005) *Preparing For Life: The Complete Guide for Transitioning to Adulthood for Those with Autism and Asperger Syndrome*. Arlington, Texas: Future Horizons Inc.
- Ballan, M. S. (2012) Parental Perspectives of Communication about Sexuality in Families of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 42(5), 676-684.
- Barry, K. (2012) Gray Matters: Autism, Impairment, and the End of Binaries. *San Diego Law Review*, 49(1).
- Bashir, A., Khurshid, S. & Qadri, F. (2014) Awareness and Problems of Parents of Children with Autism Spectrum Disorders. *International Journal of Interdisciplinary Research and Innovations*, 2(2), 42-48.
- Beddows, N. & Brooks, R. (2015) Inappropriate Sexual Behaviour in Adolescents with Autism Spectrum Disorder: What Education is Recommended and Why. *Early Intervention in Psychiatry*, 10(4), 282-289.
- Bhattacharya, J. (2010) *Contribution of Self-help Groups to the Pursuit of Women Empowerment: A Capability Approach. A District-level Study in the State of West Bengal, India*. Unpublished Doctoral thesis, University of Siena Piazza San Francesco, Italy. Retrieved (12/ 2016) from: <http://phdeconomics.wp.unisi.it/wpcontent/uploads/sites/18/2015/01/bhattacharya.pdf>
- Bhutani, S. & Vishwanath, G. (2012) Hyperbaric Oxygen and Wound Healing. *Indian Journal of Plastic Surgery*, 45(2), 316-324.

- Bitsika, V. & Sharpley, C. F. (2004) Stress, Anxiety and Depression among Parents of Children with Autism Spectrum Disorder. *Australian Journal of Guidance and Counselling*, 14(2), 151-161.
- Blanchard, C. M. (2008) The Islamic Traditions of Wahhabism and Salafiyya. *CRS Report for Congress*. Retrieved (12/ 2014) from: <https://fas.org/sgp/crs/misc/RS21695.pdf>
- Bornstein, M. H. (2006) Parenting Science and Practice. In W. Damon & R. M. Lerner (Series Eds.) & I. E. Sigel & K. A. Renninger (Vol. Eds.), *Handbook of child psychology, vol. 4: Children and Parenting* (2nd ed., pp. 3–43). Mahwah, NJ: Erlbaum.
- Boukhars, A. (2006) At the Crossroads: Saudi Arabia's Dilemmas. *Journal of Conflict Studies*, 26(1).
- Boyd, A. B. (2002) Examining the Relationship between Stress and Lack of Social Support in Mothers of Children with Autism. *Focus on Autism and Other Developmental Disabilities*, 17(4), 208-215.
- Boyd, A. B., McDonough, S. G. & Bodfish, J. W. (2012) Evidence-Based Behavioural Interventions for Repetitive Behaviours in Autism. *Journal of Autism and Developmental Disorders*, 42(6), 1236–1248.
- Braun, V. & Clarke, V. (2006) Using Thematic Analysis in Psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Brereton, A. V. (2011) Transition to Secondary School for students with an ASD. *ASD Fact Sheet 3, Victorian Department of Education and Early Childhood*. Retrieved (05/ 2014) from: <https://www.eduweb.vic.gov.au/edulibrary/public/stuman/wellbeing/autism/factsheet3.pdf>
- Brereton, A., Tonge, B., & Einfeld, S. (2006) Psychopathology in Children and Adolescents with Autism Compared to Young People with Intellectual Disability. *Journal of Autism and Developmental Disorders*, 36(7), 863-870.
- Bristol, M. M., Gallagher, J. J. & Holt, K. D. (1993) Maternal Depressive Symptoms in Autism: Response to Psychoeducational Intervention. *Rehabilitation Psychology*, 38, 3-10.
- Bristol, M. M., Gallagher, J. J. & Schopler, E. (1988) Mothers and Fathers of Young Developmentally Disabled and Nondisabled Boys: Adaptation and Spousal Support. *Developmental Psychology*, 24(3), 441-451.

- Brobst, J. B., Clopton, J. R. & Hendrick, S. S. (2009) Parenting Children with Autism: The Couple's Relationship. *Focus on Autism and Other Developmental Disabilities*, 24(1), 38-49.
- Bromley, J., Hare, D. J., Davison, K. & Emerson, E. (2004) Mothers Supporting Children with Autistic Spectrum Disorders: Social Support, Mental Health Status and Satisfaction with Services. *Journal of Autism*, 8(4), 409-423.
- Brooks, X. (2012) *Venice Film Festival: Female Film Director Defies Saudi Prejudice. Saudi Film Pioneer Haifaa al-Mansour, Who Directed Wadjda, Sometimes had to Hide in Van to Film on Location in Riyadh*. Retrieved (05/2015) from: <http://www.theguardian.com/film/2012/aug/31/venice-film-female-director-saudi-prejudice>
- Brugha T, McManus S, Meltzer H, Smith J, Scott FJ, Purdon S, Harris J, Bankart J. (2007) *Autism Spectrum Disorders in Adults Living in Households Throughout England Report from the Adult Psychiatric Morbidity Survey 2007*. The NHS Information Centre for Health and Social Care. Retrieved (04/ 2015) from: <http://content.digital.nhs.uk/catalogue/PUB01131/aut-sp-dis-adu-liv-ho-a-p-m-sur-eng-2007-rep.pdf>
- Bryman, A. (2012) *Social Research Methods*. New York: Oxford University Press.
- Burrows, K. E., Adams, C. L. & Spiers, J. (2008) Sentinels of Safety: Service Dogs Ensure Safety and Enhance Freedom and Wellbeing for Families with Autistic Children. *Qualitative Health Research*, 18 (12), 1642-1649.
- Campbell, R. (2002) *Emotionally Involved: The Impact of Researching Rape*. New York: Routledge Publisher.
- Cantu, J. (2010) *Parenting Stress on Mothers of Children with Autism*. Master's Dissertation, University of Texas- Pan American, United States of America. Retrieved (03/2015) from: ProQuest Dissertation and Thesis Database.
- Carpenter, L. (2013) *DSM5 Autism Spectrum Disorder. Guidelines & Criteria*. Retrieved (03/ 2014) from: [https://depts.washington.edu/dbpeds/Screening%20Tools/DSM-5\(ASD.Guidelines\)Feb2013.pdf](https://depts.washington.edu/dbpeds/Screening%20Tools/DSM-5(ASD.Guidelines)Feb2013.pdf)
- Carr, A., O'Reilly, G., Walsh, P. N. & McEvoy, J. (2007) *The Handbook of Intellectual Disability and Clinical Psychology Practice*. New York: Routledge publisher.

- Caspi, A., Moffitt, T. E., Morgan, J., Rutter, M., Taylor, A., Arseneault, L., Tully, L., Jacobs, C., Kim-Cohen, J. & Polo-Tomas, M. (2004) Maternal Expressed Emotion Predicts Children's Antisocial Behaviour Problems: Using Monozygotic-Twin Differences to Identify Environmental Effects on Behavioural Development. *Developmental Psychology*, 40(2), 149-161.
- CEDAW Committee, Convention on the Elimination of All Forms of Discrimination Against Women. (2007) *Reporting Guidelines of the Committee on the Elimination of Discrimination Against Women (Saudi Women for Reform)*, Retrieved (04/2014) from: <http://www2.ohchr.org/english/bodies/cedaw/docs/ngos/womenreform40.pdf>.
- Chamak, B. & Bonniau, B. (2013) Changes in the Diagnosis of Autism: how Parents and Professionals Act and React in France. *Culture, Medicine and Psychiatry*, 37(3), 405-426.
- Chaudhry, I. (2014) #Hashtags for Change: Can Twitter Promote Social Progress in Saudi Arabia. *International Journal of Communication*, 8, 943- 961.
- Cheausuwantavee, T. (2002) Sexual Problems and Attitudes toward Sexuality of Persons With and Without Disability. *Journal of Sexuality and Disability*, 20(2), 125-134.
- Chowdhury, M., Benson, B. A., & Hillier, A. (2010) Changes in Restricted Repetitive Behaviors with Age: A Study of High Functioning Adults with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders*, 4(2), 210-216.
- Cohen, L., Manion, L. & Morrison, K. (2001) *Research Method in Education*. Oxon: Routledge Publisher.
- Cohen, S. B. (2015) Leo Kanner, Hans Asperger, and the Discovery of Autism. *The Lancet*, 386, 10001, 1329-1330.
- Connell, R. W. (2003) *Gender and Power*. Cambridge: Polity Press.
- Cortez, R. M. (2011) Culture, Play, and Family: Supporting Children on the Autism Spectrum. *Young Children*, 6 (5), 94-99.
- Cox, N. B. (2014) *Parents of Individuals with Autism Spectrum Disorders: Parental Perspectives and Experiences*. Unpublished Doctoral thesis, University of Virginia, United States. Retrieved (12/ 2013) from: <http://libraprod.lib.virginia.edu/catalog/libra-oa:7650>
- Denzin, N. K. & Lincoln, Y. S. (2013) *The Landscape of Qualitative Research*. California: Sage Publication.

- Deris, A. R., DiCarlo, C., Wilson, L. F., Ota, C. & O'Hanlon, A. (2012) Investigation of Social Supports for Parents of Children with Autism. *International Journal of Early Childhood Special Education*, 4(1), 17-31.
- Diemen, R. (2012) Politics and Religion in Saudi Arabia: Does the State Control Religion or Does Religion Control the State? A critical analysis of the interaction between the Al Saud regime and the religious establishment of Saudi Arabia. *Politics and Religion in Saudi Arabia*. Retrieved (01/2017) from:
<http://www.lboro.ac.uk/media/wwwlboroacuk/external/content/schoolsanddepartments/phir/downloads/studentessayspdf/politicsandreligioneuc664/11EUC664%20essay%20-%20Renee%20Van%20Diemen%20-%20Saudi%20Arabia%20-%20Does%20the%20State%20Control%20Religion%20or%20Does%20Religion%20Control%20the%20State.pdf>
- Doumato, E. (2000) *Getting God's Ear: Women, Islam, and Healing in Saudi Arabia and the Gulf*. United States: Columbia University Press.
- Dumas, J. E., Wolf, L. C., Fisman, S. N. & Culligan, A. (1991) Parenting Stress, Child Behaviour Problems, and Dysphoria in Parents of Children with Autism, Down syndrome, Behaviour Disorders, and Normal Development. *Exceptionality*, 2, 97-110
- Dunn, M. E., Burbin, T., Bowers, C. A. & Tantleff-Dunn, S. (2001) Moderators of Stress in Parents of Children with Autism. *Community Mental Health Journal*, 37(1), 39–52.
- Dyches, T. T., Wilder, L. K., Sudweeks, R. R., Obiakor, F. E., & Algozzine, B. (2004). Multicultural Issues in Autism. *Journal of Autism and Developmental Disorders*, 34(2), 211-222.
- E-Da`wah Committee (2015) *Qur'an and People with Disabilities*. Retrieved (07/2017) from: <http://www.muslim-library.com/dl/books/English-Quran-and-People-with-Disabilities.pdf>
- Ekas, N. V., Lickenbrock, D. M. & Whitman, T. L. (2010) Optimism, Social Support, and Well-Being in Mothers of Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 40(10), 1274–1284.
- Elbayar, K. (2010) Replacing Traditions: Islamic law in a Modern World. *International Affairs Review*. Retrieved (07/2014) from: <http://www.iar-gwu.org/node/23>
- Elder, J. H. & D'Alessandro, T. (2009). Supporting Families of Children with Autism Spectrum Disorders: Questions Parents Ask and What Nurses Need to Know. *Journal of Paediatric Nursing*, 35(4), 240-253.

- El-Solh, C.F. and Mabro, J. (Eds) (1994) *Muslim Women's Choices: Religious Belief and Social Reality (Cross-Cultural Perspectives on Women)*. Providence: Berg Publications.
- Esbensen, A. J., Seltzer, M. M., Lam, K. S. L., & Bodfish, J. W. (2009) Age-related Differences in Restricted Repetitive Behaviors in Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 39(1), 57-66.
- Etherington, K. (2007) Ethical Research in Reflexive Relationships. *Qualitative Inquiry*, 13(5), 599-616.
- Fatany, S. (2007) *Saudi Women: Towards a New Era*. Riyadh: Ghainaa Publisher.
- Fattah, M. H. (2006) *Daring to Use the Silver Screen to Reflect Saudi Society*. The New York Times. Retrieved (04/ 2014) from:
<http://www.nytimes.com/2006/04/28/world/middleeast/28saudi.html>
- Fecteau, S., Mottron, L., Berthiaume, C., & Burack, J. A. (2003) Developmental Changes of Autistic Symptoms. *Autism*, 7(3), 255-268.
- Field, K. (2011) *The importance of Research for Education's Future*. Retrieved (12/ 2016) from: <http://www.expressandstar.com/education/2011/06/14/the-importance-of-research-for-educations-future/>
- Fischbach, G. D. (2007) Leo Kanner's 1943 Paper on Autism. *Safar, Simon foundation Autism Research Initiative*. Retrieved (07/ 2014) from: <https://sfari.org/news-and-opinion/classic-paper-reviews/2007/leo-kanners-1943-paper-on-autism-commentary-by-gerald-fischbach>
- Flaharty, M. R. (2013) *Assessing Expressed Emotion Influences on Autistic Symptoms/Behaviours: A School Social Worker Perspective*. Unpublished Master's dissertation, St. Catherine University and the University of St. Thomas St. Paul, Minnesota, United States of America. Retrieved (12/2016) from:
http://sophia.stkate.edu/cgi/viewcontent.cgi?article=1177&context=msw_papers
- Fong, L., Wilgosh, L., & Sobsey, D. (1993) The Experience of Parenting an Adolescent with Autism. *International Journal of Disability, Development and Education*, 40, 105-113.
- Gabriels, R. L., & Hill, D. E. (2007) *Growing Up with Autism: Working with School- age Children and Adolescents*. New York: The Guilford Press.

- Gallagher, S., Phillips, A. C., Lee, H. & Carroll, D. (2015) The Association Between Spirituality and Depression in Parents Caring for Children with Developmental Disabilities: Social Support and/or Last Resort. *Journal of Religion and Health*, 54(1), 358–370.
- Gautam, S. & Jain, N. (2010) Indian Culture and Psychiatry. *Indian Journal of Psychiatry*, 52(1), 112-117.
- Georghiou, L. (2015) Value of Research: Policy Paper by the Research, Innovation, and Science Policy Experts (RISE). Retrieved (12/ 2016) from: https://ec.europa.eu/research/innovation-union/pdf/expert-groups/rise/georghiou-value_research.pdf
- Geraldina, E. (2015) Teachers' Knowledge and Perceived Challenges of Teaching Children with Autism in Tanzanian Regular Primary Schools. *International Journal of Academic Research and Reflection*, 3(5), 36-47.
- Ghanizadeh, A. (2012) Hyperbaric Oxygen Therapy for Treatment of Children with Autism: a Systematic Review of Randomized Trials. *Medical Gas Research*, 2(13), 1-8.
- Gill, M. J., & Harris, S. L. (1991) Hardiness and Social Support as Predictors of Psychological Discomfort in Mothers of Children with Autism. *Journal of Autism and Developmental Disorders*, 21(4), 407-416.
- Gillberg C, Steffenburg S. (1987) Outcome and Prognostic Factors in Infantile Autism and Similar Conditions: A Population-Based Study of 46 Cases Followed through Puberty. *Journal of Autism Developmental Disorder*, 17(2), 273-287.
- Goldman, A. I. (2012) *Theory of Mind*. Oxford Handbook of Philosophy and Cognitive Science. Retrieved (07/2017) from: http://diabeto.enseeiht.fr/download/perception/Goldman_2012.pdf
- Gray, D. E. & Holden, W. J. (1992) Psychosocial Well-being among the Parents of Children with Autism. *Australia and New Zealand Journal of Developmental Disabilities*, 18(2), 83-93.
- Gray, D. E. (2014) *Doing Research in the Real World*. London: Sage Publisher.
- Greenberg, J. S., Seltzer, M. M., Krauss, M. W., Chou, R. J.-A., & Hong, J. (2004) The Effect of Quality of the Relationship between Mothers and Adult Children with Schizophrenia, Autism, or Down Syndrome on Maternal Well-Being: The Mediating Role of Optimism. *American Journal of Orthopsychiatry*, 7 (1), 14-25.

- Guba, E. G. (1981) Criteria for Assessing the Trustworthiness of Naturalistic Inquiries. *Education, Communication and Technology Journal*, 29, 75-91.
- Guba, E. G. & Lincoln, Y. S. (1998) Competing Paradigms in Qualitative Research. In N. K. Denzin & Y. S. Lincoln (Eds.). *The landscape of qualitative research: Theories and issues* (p. 195-220). Thousand Oaks, CA: Sage.
- Guvercin, H. (2008) People with Disabilities from an Islamic Perspective. Retrieved (07/2017) from: <http://www.fountainmagazine.com/Issue/detail/People-with-Disabilities-from-an-Islamic-Perspective>
- Ha, J. H., Greenberg, J. S. & Seltzer, M.M. (2011) Parenting a Child with a Disability: The Role of Social Support for African American Parents. *PubMed Central Journal*, 92(4), 405-411.
- Hadadian, A. (1994). Stress and Social Support in Fathers and Mothers of Young Children With and Without Disabilities. *Early Education and Development*, 5(3), 226-235.
- Hamdan, A. (2005) Women and Education in Saudi Arabia: Challenges and Achievements. *International Education Journal*, 6(1), 42-64.
- Happe, F. G.E. (2009) Understanding Minds and Metaphors: Insights from the Study of Figurative Language in Autism. *Metaphor and Symbolic Activity*, 10(4), 275-295.
- Hartley, M (2016) *Politics and Culture: Masters and slaves*. Retrieved (12/ 2016) from: <http://mickhartley.typepad.com/blog/2016/08/masters-and-slaves.html>
- Hastings, R. P. & Johnson, E. (2001) Stress in UK Families Conducting Intensive Home-Based Behavioural Intervention for Their Young Child with Autism. *Journal of Autism and Developmental Disorders*, 31, 327-336.
- Hatch, J. A. (2002) *Doing Qualitative Research in Education Settings*. New York: State University New York Press.
- Hegghammer, T. & Lacroix, S. (2007) Rejectionist Islamism in Saudi Arabia: The Story of Juhayman Al-Utaybi Revised. *International Journal of Middle East Studies*, 39, 103-122.
- Herman, S. E. & Thompson, L. (1995) Families' Perception of Their Resources for Caring for Children with Developmental Disabilities. *Mental Retardation*, 33(2), 73-83.
- Higashida, N. (2013) *The Reason I Jump*. London: Hodder & Stoughton, Sceptre.
- Hoare, J. (2009) Women's Rights Movements and Education for All: Connections and Disconnections. *Beyond Access: Gender, Education and Development*. Retrieved (03/ 2017) from: http://www.ungei.org/resources/files/Equals_23_Low_Res_TP.pdf

- Hoefman, R., Payakachat, N., Exel, J. V., Kuhlthau, K., Kovacs, E., Pyne, J. & Tilford, J. M. (2014) Caring for a Child with Autism Spectrum Disorder and Parents' Quality of Life: Application of the CarerQol. *Journal of Autism Development Disorder*, 44(8), 1933-1945.
- House, J. S., Umberson, D. & Landis, K. R. (1988) Structures and Processes of Social Support. *Annual Review of Sociology*, 14, 293-318.
- Howlin, P. (2015) *Autism*. Retrieved (04/ 2016) from:
<http://www.intellectualdisability.info/diagnosis/articles/autism>
- Hume, K., Boyd, B. A., Jill V. Hamm, J. V. & Kucharczyk, S. (2014) Supporting Independence in Adolescents on the Autism Spectrum. *Journal of Remedial and Special Education*, 35(2).
- Hussein, H., Taha, G. RA. & Almanasef, A. (2011) Characteristics of Autism Spectrum Disorders in a Sample of Egyptian and Saudi Patients: Transcultural Cross Sectional Study. *Child and Adolescent Psychiatry and Mental Health*, 5(34), 1-12.
- Hutton, A. M. & Caron, S. L. (2005) Experiences of Families with Children with Autism in Rural New England. *Focus on Autism and Other Developmental Disorder*, 20(3), 180-189.
- International crisis group. (2004) Saudi Arabia Backgrounder: Who Are the Islamists? *ICG Middle East Report N31*. Retrieved (06/2014) from:
<https://www.crisisgroup.org/middle-east-north-africa/gulf-and-arabian-peninsula/saudi-arabia/saudi-arabia-backgrounder-who-are-islamists>
- Jaleel, E. M., Shaik Ismail, S. F. & Christopher, A. A. (2016) Representation of Working Women in Zoe Ferraris' City of Veils. *European Journal of English Language and Literature Studies*, 4(5), 23-35.
- Jawhar, S. (2014) Saudi Women No Longer Confined to Their Conventional Roles. *Arab New*. Retrieved (11, 2015) from: <http://www.arabnews.com/saudi-women-no-longer-confined-their-conventional-roles>
- Jawhar, S. S. (2012) Citizenship Rules Victimize Saudi Mothers and Non-Saudi Children. *Arab News*. Retrieved (02/2016) from: <http://www.arabnews.com/citizenship-rules-victimize-saudi-mothers-and-non-saudi-children>
- Jayachandran, S. (2014) *The Roots of Gender Inequality in Developing Countries*. North-Western University, Annual Review of Economics. Retrieved (06/2016) from:
http://faculty.wcas.northwestern.edu/~sjv340/roots_of_gender_inequality.pdf

- Jones, E. A. & Carr, E. G. (2004) Joint Attention in Children with Autism: Theory and Intervention. *Focus on Autism and Other Developmental Disabilities*, 19(1), 13-26.
- Kanner, L. (1943) Autistic Disturbance of Affective Contact. *Pathology*, 217- 250.
- Karloak, M. (2012) Bahraini Women in the 21st Century: Disputed Legacy of the Unfinished Revolution. *Journal of International Women's Studies*, 13(5), 5-16.
- Karst, J. S. (2014) *Parent and Families Outcomes of an Empirically Validated Social Skills Intervention for Adolescents with Autism Spectrum Disorders*. Unpublished Doctoral thesis, Milwaukee University, Wisconsin, United States. Retrieved (10/ 2015) from: http://epublications.marquette.edu/cgi/viewcontent.cgi?article=1349&context=dissertations_mu
- Kelly, S. (2009) Recent Gain and New Opportunities for Women's Rights in the Gulf Arab States. *Women's Rights in the Middle East and North Africa*. Retrieved (04/2014) from: <http://projects.iq.harvard.edu/violenceagainstwomen/publications/recent-gains-and-new-opportunities-womens-rights-gulf-arab-states>
- Kemmis, S. & Taggart, R. (1988) *The Action Research Planner*. 3rd edition. Geelong, Australia: Deakin University Press.
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C. & Pellicano, E. (2015) Which Terms Should be Used to Describe Autism? Perspectives from the UK Autism Community. *Autism*, 20(4), 442-462.
- Kerns, K. & Siklos, S. (2006) Assessing Need for Social Support in Parents of Adolescents with Autism and Down Syndrome. *Journal of Autism Developmental Disorder*, 36(7), 921-933.
- Khader, S. J. (2009) Adaptive Preferences and Procedural Autonomy. *Journal of Human Development and Capabilities*, 10(2), 169-187.
- Khan, H. (2013) Practitioner's Guide: Islamic Law. *INPROL - International Network to Promote the Rule of Law*. Retrieved (01, 2017) from: http://inprol.org/sites/default/files/publications/2013/islamic_law_guide-july_2013_final_0.pdf
- Khan, S. (2017) *Saudi Film Festival Rolls Out the Red Carpet in Dhahran*. Retrieved (01/ 2017) from: <http://www.arabnews.com/node/1075306/saudi-arabia>
- Kika, M. (2014) Intellectual Disability in Children with Autism Spectrum. *International Journal of Humanities Social Sciences and Education (IJHSSE)*, 1(10), 1-4.
- King, N. (1998) 'Template Analysis', in G. Symon & C. Cassell (eds.) *Qualitative Methods and Analysis in Organisational Research*. Sage: London.

- Kleist, C. (2013) A Discourse Ethics Defence of Nussbaum's Capabilities Theory. *Journal of Human Development and Capabilities*, 14(2), 266-284.
- Koegel, L.K. & Lazebnik, C. (2009) *Growing Up On the Spectrum: A Guide to Life, Love, and Learning for Teens and Young Adults with Autism and Asperger's*. New York: The Penguin Group.
- Konstantareas, M. M. (1991) Autistic, Learning Disabled and Delayed Children's Impact on Their Parents. *Canadian Journal of Behavioural Science*, 23(3), 358-375.
- Krauss, M. W., Upshur, C. C., Shonkoff, J. P. & Hauser-Cram, P. (1993) The Impact of Parent Groups on Mothers of Infants with Disabilities. *Journal of Early Intervention*, 17(1), 8-20.
- Kuek, C. Y. & Tay, E. S. (2013) Religious Conversions and Conflicts between Civil and Islamic Law of Inheritance in Malaysia. *Malayan Law Journal*.
- Kulage, K. M., Smaldone, A. M. & Cohn, E. G. (2014). How Will DSM-5 Affect Autism Diagnoses? A Systematic Literature Review and Meta- Analysis. *Journal of Autism developmental disorder*, 44(8), 1918-1932.
- Kvale, S. (2006) Dominance through Interviews and Dialogues. *Dialogical Interview Research*, 12(3), 480-500.
- Lasgaard, M., Nielsen, A., Eriksen, M. E. & Goossens, L. (2010) Loneliness and Social Support in Adolescents Boys with Autism Spectrum Disorder. *Journal of Autism Developmental Disorder*, 40(2), 218-226.
- Le Renard, A. (2008) Only for Women: Women, the State, and Reform in Saudi Arabia. *Middle East Journal*, 62(4), 610-629.
- Lederman, N.G. & Abell, S.K. (2014) *Handbook of Research on Science Education*. New York: Routledge.
- Lee, R. M. (1993) *Doing Research on Sensitive Topics*. London: Sage Publication.
- Liamputtong, P. (2007) *Researching the Vulnerable*. London: Sage Publication.
- Lin, L., Orsmond, G. I., Coster, W. J., & Cohn, E. S. (2011) Families of Adolescents and Adults with Autism Spectrum Disorders in Taiwan: The Role of Social Support and Coping in Family Adaptation and Maternal Well-Being. *Research in Autism Spectrum Disorders* 5, 144-156.
- Long, D. E. (2005) *Culture and Customs of Saudi Arabia*. Westport, Conn: Greenwood Press.

- Lopez, B. R., Lincoln, A. J., Ozonoff, S., & Lai, Z. (2005). Examining the Relationship between Executive Functions and Restricted, Repetitive Symptoms of Autistic Disorder. *Journal of Autism Disorder*, 35(4), 445-460.
- Lowry, L. (2015) *Imitation with Children on the Autism Spectrum: More than Just a Game of Copycat*. Retrieved (12/ 2017) from: <http://www.hanen.org/Helpful-Info/Articles/Imitation-with-Children-on-the-Autism-Spectrum.aspx>
- Ludlow, A., Skelly, C. & Rohleder, P. (2011) Challenges Faced by Parents of Children Diagnosed with Autism Spectrum Disorder. 702-711
- Lyons, V., & Fitzgerald, M. (2007) Asperger (1906–1980) and Kanner (1894–1981), The Two Pioneers of Autism. *Journal of Autism Disorder*, 37, 2022-2023.
- Mancil, G. R., Boyd, B. A. & Bedesem, P. (2009) Parental Stress and Autism: Are There Useful Coping Strategies? *Education and Training in Developmental Disabilities*, 44(4), 523-537.
- Mandy, W., Charman, T., Puura, K. & Skuse, D. (2013) Investigating the Cross-Cultural Validity of DSM-5 Autism Spectrum Disorder: Evidence from Finnish and UK Samples. *Autism Journal*, 18(1).
- Martin, D. N. & Bassman, M. (2012) *The Ever-Changing Social Perception of Autism Spectrum Disorders in the United States*. Retrieved (8/ 2016) from: <http://uncw.edu/csurf/Explorations/documents/DanielleMartin.pdf>
- McGovern, C. W., & Sigman, M. (2005) Continuity and Change from Early Childhood to Adolescence in Autism. *Journal of Child Psychology and Psychiatry*, 46(4), 401-408.
- Mcevers, K. (2009) *Ambitious New University Opens In Saudi Arabia*. Retrieved (12/ 2015) from: <http://www.npr.org/templates/story/story.php?storyId=120448256>
- Meadan, H., Halle, J.W., Ebata, A.T. (2010) Families with Children who have Autism Spectrum Disorders: Stress and Support. *Council for Exceptional Children*, 77(1), 7-36.
- Meijer, R. (2010) The Gender Segregation (ikhtilat) Debate in Saudi Arabia: Reform and the Clash between Ulma and Liberals. *Journal of Islamic Studies*, 30, 2-32.
- Melrose, M. (2002) ‘Labour Pains: Some Consideration on the Difficulties of Researching Juvenile Prostitutions’. *International Journal of Social Research Methodology*, 5(1), 333-51.

- Memari, A. H., Panahi, N., Ranjbar, E., Moshayedi, P., Shafiei, M., Kordi, R. & Ziaee, V. (2015) Children with Autism Spectrum Disorder and Patterns of Participation in Daily Physical and Play Activities. *Neurology Research International*.
- Mendoza, T. (2007) *Impact of Social Support, Socio- Economic Status, and Ethnicity on Stress Level of Parents Who Have Children with Autism*. Unpublished Master's dissertation, University of Texas, United States of America. Retrieved (05/ 2014) from: ProQuest Dissertation and Thesis Database.
- Merriam, S. B. (1998) *Qualitative Research and Case Study Applications in Education: Revised and Explained from Case Study Research in Education*. San Francisco: Jossey-Bass Publisher.
- Miller, T. & Bell, L. (2002) 'Consenting to what? Issues of Access, Gate- Keeping and "Informed" Consent'. Pp. 53- 69. In *Ethics in Qualitative Research*, edited by M. Mauthner, M. Birch, J. Jessop & T. Miller. London: Sage Publication.
- Mitra, S. (2006) The Capability Approach and Disability. *Journal of Disability Policy Studies*, 16(4), 236-247.
- Moghadam, V. M. (2003) *Modernizing women: Gender and Social Change in the Middle East*. Boulder, USA: Lynne Rienner Publishing.
- Montes, G. & Halterman, J. S. (2006) Characteristics of School-age Children with Autism. *Journal of Developmental and Behavioural Paediatrics*, 27(5), 379-385.
- Morse, J.M. & Field, P.A. (1995) *Qualitative Research Methods for Health Professionals*. Thousand Oaks, CA: Sage Publication.
- Moustakas, C. (1994) *Phenomenological Research Methods*. New York: Sage Publication.
- Mtango, S. (2004) A State of Oppression? Women's Rights in Saudi Arabia. *Asia-Pacific Journal on Human Rights and the Law*, 5(1), 49-67.
- Mugno, D., Ruta, L., D'Arrigo, V.G., & Mazzone, L. (2007) Impairment of Quality of Life in Parents of Children and Adolescents with Pervasive Developmental Disorders. *BioMed Central Ltd*, 5(22).
- Myers, M. D. (2009) *Qualitative Research in Business and in Management*. London: Sage Publication.
- National Autistic Society (2011). *Autism Spectrum Disorders: A Resource Pack for School Staff*. Retrieved (12/2016) from:
file:///C:/Users/Wid%20Daghustani/Downloads/ASDs-a-resource-pack-for-school-staff-Nov2011.pdf

- National Health System, NHS. (2012) *Causes of Autism and Asperger Syndrome*. Retrieved (10/ 2014) from: <http://www.nhs.uk/conditions/autistic-spectrum-disorder/Pages/Causes.aspx>
- Noman, M. (2016) *The Funny Side of Saudi*. Retrieved (09/ 2015) from: <http://www.bbc.co.uk/news/blogs-trending-35687711>
- Nussbaum, M. C. (2000) *Women and Human Development: The Capability Approach*. Cambridge, New York: Cambridge University Press.
- Nussbaum, M. C. (2000) Women's Capabilities and Social Justice. *Journal of Human Development*, 1(2), 219-247.
- Nussbaum, M. C. (2001) Symposium on Amartya Sen's Philosophy: 5 Adaptive Preferences and Women's Options. *Economics and Philosophy*, 17, 67-88.
- Nussbaum, M. C. (2003) Capabilities as Fundamental Entitlements: Sen and Social Justice. *Feminist Economics*, 9(2), 33-59.
- Nussbaum, M. C. (2004) Beyond the Social Contract: Capabilities and Global. *Oxford Development Studies*, 32(1), 3-18.
- Nussbaum, M. C. (2006) *Frontiers of Justice: Disability, Nationality, Species Membership*. Boston: The Belknap Press.
- Nussbaum, M. C. (2009) The Capabilities of People With Cognitive Disabilities. *Journal Compilation Metaphilosophy LLC and Blackwell Publishing Ltd*, 40(3), 331-351
- Nussbaum, M. C. (2011) *Creating Capabilities: The Human Development Approach*. Boston: Harvard University Press.
- Nussbaum, M.C. (1999) *Sex and Social Justice*. Oxford: Oxford University Press.
- O'Brien, S. (2016) Families of Adolescents with Autism: Facing the Future. *Journal of Paediatric Nursing*, 31(2), 204-213.
- Offenhauer, P. (2005) Women in Islamic Societies: a Selected Review of Social Scientific Literature. *Federal Research Division, Library of Congress*. America. Retrieved (10/ 2015) from: https://www.loc.gov/rr/frd/pdf-files/Women_Islamic_Societies.pdf
- Okin, S. M. (1989) *Justice, Gender, and the Family*. New York: Basic book Publisher.
- Oliver, M. (1990) *The Individual and Social Models of Disability*. Retrieved (08/ 2017) from: <http://disability-studies.leeds.ac.uk/files/library/Oliver-in-soc-dis.pdf>.
- Opdenakker, R. (2006) Advantages and Disadvantages of Four Interview Techniques in Qualitative Research, *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, 9 (4), 1-9. Retrieved (08/2017) from <http://www.qualitative-research.net/index.php/fqs/article/view/175/391>.

- Oppenheim, A. N. (2001) *Questionnaire Design, Interviewing and Attitude Measurement*. London: Continuum.
- Orozco, T. (2014) *Impact of Birth Order on Autism Spectrum Disorder Children's Typically-Developing Siblings*. Master's dissertation, California State University, San Bernardino, The United States of America. Retrieved (11/ 2013) from: <http://scholarworks.lib.csusb.edu/cgi/viewcontent.cgi?article=1126&context=etd>
- Orsmond, G. I., Lin, L. & Seltzer, M. M. (2007) Mothers of Adolescents and Adults with Autism: Parenting Multiple Children with Disabilities. *Intellectual and Developmental Disability*, 45(2), 257-270.
- Otokpa, O. (2014) *The Unseen Terrorist*. Bloomington: AuthorHouse Publisher.
- Pandalangat, N. (2011) *Cultural Influences on Help-Seeking, Treatment and Support for Mental Health Problems – A Comparative Study using a Gender Perspective*. Unpublished Doctoral thesis, University of Toronto, Canada. Retrieved (11/2015) from: https://tspace.library.utoronto.ca/bitstream/1807/31890/3/Pandalangat_Nalini_201111_PhD_thesis.pdf
- Pearson, M. (2015) *Polls Open in Saudi Arabia, First Time Women Allowed to Vote*. Retrieved (05/ 2016) from: <http://edition.cnn.com/2015/12/12/world/saudia-arabia-women-vote/>
- Plant, O. (2011) *A Study of Mothers of High School Aged Children with Autism: Their Experience with Social Support*. Doctoral thesis, Capella University, United States of America. Retrieved (03/2015) from: ProQuest Dissertation and Thesis Database.
- Preece, D. (2008) Social Care Support Services in England for Children and Adults with Autism Spectrum Disorders and Their Families. *Journal of Special Education and Rehabilitation*, 9(34), 63-72.
- Prizant, B. M. & Rydell, P. (1984) Analysis of Functions of Delayed Echolalia in Autistic Children. *Journal of Speech and Hearing Research*, 27, 183-192.
- Public Health Institute. (2001) *Autism Spectrum Disorder: Needs Assessment Report*. National Health System NHS. Retrieved (03/ 2014) from: <http://www.gov.scot/resource/doc/1095/0076895.pdf>

- Rajkhan, S. F. (2014) *Women in Saudi Arabia Status, Rights, and Limitations*. Unpublished Master's dissertation, University of Washington Bothell. United States of America. Retrieved (01/2017) from:
<https://digital.lib.washington.edu/researchworks/bitstream/handle/1773/25576/Rajkhan%20-%20Capstone.pdf?sequence=1>
- Rao, T.S. S. & Andrade, C. (2011) The MMR Vaccine and Autism: Sensation, Refutation, Retraction, and Fraud. *Indian Journal of Psychiatry*, 53(2), 95-96.
- Ratner, C. (2002) Subjectivity and Objectivity in Qualitative Methodology. *Forum: Qualitative Social Research*, 3(3). Retrieved (01/ 2017) from: <http://www.qualitative-research.net/index.php/fqs/article/viewArticle/829/1800>
- Reiersen, A. M. & Todd, R. D. (2014). Co-occurrence of ADHD and Autism Spectrum Disorders: Phenomenology and Treatment. *Expert Review of Neurotherapeutics*, 8(4), 657-669.
- Renty J. & Roeyers, H. (2006) Satisfaction with Formal Support and Education for Children with Autism Spectrum Disorder: The Voices of the Parents. *Child Care Health Development*, 32(3), 371-385.
- Rex, C. (2014) *An Anti-Bullying Intervention for Children with Autism Spectrum Disorder*. CMC Senior Thesis. Retrieved (01/ 2017) from:
http://scholarship.claremont.edu/cgi/viewcontent.cgi?article=1902&context=cmc_theses
- Riedy, R. T. (2013) *Multilingual Creative Reformists: Saudi Arabian Women's Ingenuity in Overcoming Economic, Religious and Cultural Barriers to Career Success*. Unpublished master's dissertation, University of Washington, USA. Retrieved (01/ 2014) from:
https://dlib.lib.washington.edu/researchworks/bitstream/handle/1773/23624/Riedy_washington_0250O_11955.pdf?sequence=1&isAllowed=y
- Robeyns, I. (2003) The Capability Approach: An Interdisciplinary Introduction. Retrieved (01/ 2017) from:
http://commonweb.unifr.ch/artsdean/pub/gestens/f/as/files/4760/24995_105422.pdf
- Rossignol, D. A., Bradstreet, J. J., Dyke, K. V., Schneider, C., Freedenfeld, S. H., O'Hara, N., Cave, S., Buckley, J. A., Mumper, E. A. & Frye, R. E. (2012). Hyperbaric Oxygen Treatment in Autism Spectrum Disorders. *Medical Gas Research*, 2.
- Runswick-Cole, K., Mallett, R. & Timimi, S. (2016) *Re-Thinking Autism: Diagnosis, Identity and Equality*. London: Jessica Kingsley Publisher.

- Russell, A. J., Mataix- Cols, D., Anson, M. & Murphy, D. G. M. (2005) Obsessions and Compulsions in Asperger Syndrome and High-functioning Autism. *The British Journal of Psychiatry*, 186(6), 525-528.
- Rutter, M. (2005) Autism Research: Lessons from the Past and Prospects for the Future. *Journal of Autism and Developmental Disorders*, 35(2), 241-57.
- Ryan, G. & Bernard, H. R. (2003). Techniques to Identify Themes. *Field Methods*, 15(1), 85-109.
- Ryan, T. (2005) Reflexivity and the Reader: an Illumination. *The Ontario Action Research*, Retrieved (01/2017) from: <http://oar.nipissingu.ca/PDFS/V712.pdf>.
- Saad, A. G. & Goldfeld, M. (2009) Echolalia in the Language Development of Autistic Individuals: a Bibliographical Review. *Pró-Fono R. Atual. Cient*, 21(3). Retrieved (05/2014) from: http://www.scielo.br/scielo.php?pid=s010456872009000300013&script=sci_arttext&tlng=en
- Sanders, J. L. & Morgan, S. B. (1997) Family Stress and Management as Perceived by Parents of Children with Autism or Down Syndrome: Implications for Intervention. *Child and Family Behaviour Therapy*, 19(4), 15-32.
- Schieve, L.A., Gonzalez, V., Boulet, S.L., Visser, S.N., Rice, C.E., Van Naarden Braun K. & Boyle, C.A. (2012) Concurrent Medical Conditions and Health Care Use and Needs Among Children with Learning and Behavioural Developmental Disabilities, National Health Interview Survey, 2006-2010. *Journal Research in Developmental Disabilities*, 33(2), 467- 476.
- Schriber, R. A., Robins, R. W. & Solomon, M. (2014) Personality and Self-Insight in Individuals with Autism Spectrum Disorder. *Journal of Personality and Social Psychology*, 106(1), 112–130.
- Seidman, I. (2006) *Interviewing as Qualitative Research: A Guide for Researchers in Education and the Social Sciences*. New York: Teachers College Press.
- Seltzer, M. M.; Krauss, M.; Orsmond, G. & Vestal, C. (2001) Families of Adolescents and Adults with Autism: Uncharted Territory. *International Review of Research in Mental Retardation*, 23, 267- 294.
- Sen, A. (1999) *Development as Freedom*. Oxford: Oxford University Press.
- Sen, A. (2009) *The Idea of Justice*. London: Penguin Books.
- Seneca, L. A. (2010) *Natural Questions*. Chicago: University Of Chicago Press.

- Sharpley, C. F., Bitsika, V. & Efremidis, B. (1997) Influence of Gender, Parental Health, and Perceived Expertise of Assistance Upon Stress, Anxiety, and Depression among Parents of Children with Autism. *Journal of Intellectual and Developmental Disability*, 22, 19-28.
- Shenton, A. K. (2004) Strategies for Ensuring Trustworthiness in Qualitative Research Projects. *Education for Information*, 22, 63–75.
- Sicile-Kira, C. (2004) Autism Spectrum Disorder: The Complete Guide to Understanding Autism, Asperger's Syndrome, Pervasive Developmental Disorder, and other ASDs. NY: The Berkley Publishing Group.
- Sicile- Kira, C. (2006) *Adolescents on the Autism Spectrum: A Parent's Guide to the Cognitive, Social, Physical, and Transition Needs of Teenagers with Autism Spectrum Disorders*. New York: The Penguin Group.
- Sicile-Kira, C. (2011) *What IQ Tests Really Tell Us about Children with Autism: How to Better Administer Psychological Assessments to Children with Autism*. Retrieved (02/2014) from: <https://www.psychologytoday.com/blog/the-autism-advocate/201103/what-iq-tests-really-tell-us-about-children-autism>
- Siewertsen, C., French, E. & Teramoto, M. (2015) Autism Spectrum Disorder and Pet Therapy. *Advances Journal*, 29(2), 22-25.
- Sinclair, J. (2013) Why I Dislike “person first” Language. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1(2).
- Singh, G. (2013) *Women in the Gulf: An Assessment of Bahrain and Saudi Arabia*. Saarbrucken: Scholar's Press.
- Singh, N. N., Lancioni, G. E., Manikam, R., Winton, A. S.W., Singh, A. N.A., Singh, J. & Singh, A. D.A. (2011). A Mindfulness-Based Strategy for Self-Management of Aggressive Behaviour in Adolescents with Autism. *Research in Autism Spectrum Disorders*, 5(3), 1153-1158.
- Sivberg, B. (2002) Coping Strategies and Parental Attitudes, A Comparison of Parents with Children with Autistic Spectrum Disorders and Parents with Non-Autistic Children. *International Journal of Circumpolar Health*, 1, 36-50.
- Smith, L. E., Greenberg, J. S., Seltzer, M. M. (2012) Social Support and Well-being at Mid-Life Among Mothers of Adolescents and Adults with Autism Spectrum Disorders. *Journal of Autism Developmental Disorder*, 42(9), 1818-1826.

- Smith, L. E., Greenberg, J. S., Seltzer, M. M., & Hong, J. (2008) Symptoms and Behaviour Problems of Adolescents and Adults with Autism: Effects of Mother–Child Relationship Quality, Warmth, and Praise. *American Journal on Mental Retardation*, 113(5), 387-402.
- Smith, L. E., Seltzer, M. M., Flusberg, H. T., Greenberg, J. S. & Carter, A. S. (2008) A Comparative Analysis of Well-Being and Coping among Mothers of Toddlers and Mothers of Adolescents with ASD. *Journal of Autism Developmental Disorder*, 38(5), 876-889.
- Smith, L.E., Greenberg, J.S., & Mailick, M.R. (2014) The Family Context of Autism Spectrum Disorder: Influence on Behavioural Phenotype and Quality of Life. *Child and Adolescent Psychiatric Clinics of North America*, 23(1), 143-155.
- Smith, M., Segal, J., & Hutman, T. (2013) *Helping Children with Autism: Treatment Strategies and Parenting Tips*. Retrieved (02/ 2014) from:
http://www.helpguide.org/mental/autism_help.htm.
- Sparks, B. F., Friedman, S. D., Shaw, D. W., Aylward, E. H., Echelard, D., Artru, A. A., Maravilla, K. R., Giedd, J. N., Munson, J., Dawson, G. & Dager, S. R. (2002) Brain Structural Abnormalities in Young Children with Autism Spectrum Disorder. *Journal of the American Academy of Neurology*, 59 (2), 184-192.
- Stewart, F. (2004) ‘Groups and Capabilities’, Paper Presented at Fourth Conference on the Capability Approach: Enhancing Human Security, University of Pavia, Italy.
 Retrieved (01/ 2017) from:
http://biblioteca.hegoa.ehu.es/system/ebooks/15359/original/Groups_and_Capab
- Stillman, W. (2008) *What's All The Confusion About Autism?* Retrieved (07/ 2017) from:
<https://www.williamstillman.com/archive/whats-all-the-confusion-about-autism.php>
- Stone, W. L., Ousley, O. Y., Yoder, P. J., Hogan, K. L. & Hepburn, S. L. (1997). Nonverbal Communication in Two- and Three-Year-Old Children with Autism. *Journal of Autism and Developmental Disorders*, 27(6), 677-696.
- Stribling, P., Rae, J., Dickerson, P. & Dautenhahn, K. (2006) “Spelling it Out”: The Design, Delivery, and Placement of Delayed Echolalic Utterances by a Child with an Autistic Spectrum Disorder. *Issues in Applied Linguistics*, 15(1), 3-32.
- Strunk, J. A. (2011) *Managing the Healthcare Needs of Adolescents with Autism Spectrum Disorder: The Parents’ Experience*. Doctoral thesis, Virginia Commonwealth University. Richmond, Virginia, United States of America. Retrieved (03/2014) from:
<http://scholarscompass.vcu.edu/cgi/viewcontent.cgi?article=3559&context=etd>

- Summaries, S. (2012) *Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008*. Retrieved (03/ 2015) from:
<https://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm>
- Swift, V, D., James E. L., Kippen, S. & Liamputtong, P. (2009) Researching Sensitive Topics: Qualitative Research as Emotion Work. *Qualitative Research*, 9(1), 61-79.
- Szalavitz, M (2002) *Why Autistic Kids Make Easy Targets for School Bullies: Bullying Can Lead to Depression, Low Grades, Behavioural Problems and Even Physical Illness Because of the Stress It Causes — and Kids with Autism May Be Suffering the Brunt of the Harm*. Retrieved (04/ 2017) from:
<http://healthland.time.com/2012/09/05/why-autistic-kids-make-easy-targets-for-school-bullies/>
- Taylor, C. & Albasri, W. (2014) The Impact of Saudi Arabia King Abdullah’s Scholarship Program in the U.S. *Open Journal of Social Sciences*, 2, 109-118.
- Terzi, L. (2004) The Social Model of Disability: A Philosophical Critique. *Journal of Applied Philosophy*, 1(2), 141-157.
- Teschl, M. & Comim, F. (2005) Adaptive Preferences and Capabilities: Some Preliminary Conceptual Explorations. *Review of Social Economy*, 63(2), 230-246.
- The Global Gender Gap Report. (2013) *The World Economic Forum*. Geneva: Switzerland. Retrieved (05/2015) from:
http://www3.weforum.org/docs/WEF_GenderGap_Report_2013.pdf
- The Guardian, (2014) Two Women Referred to ‘Terror’ Court for Driving in Saudi Arabia. Retrieved (12/2016) from: <https://www.theguardian.com/world/2014/dec/25/women-charged-saudi-arabia-driving-ban-terror-court>
- The National Archive (2005) *Data Protection Act 1998*. Retrieved (03/ 2015) from:
<http://www.legislation.gov.uk/ukpga/1998/29/schedule/1>
- Thibault, R. (2014) Can Autistics Redefine Autism? The Cultural Politics of Autistic Activism. *Trans-Scripts*, 4. Retrieved (02/2015) from:
http://sites.uci.edu/transcripts/files/2014/10/2014_04_04.pdf
- Thomas, P. Y. (2010) *Towards Developing a Web-Based Blended Learning Environment at the University of Botswana*. University of South Africa, Pretoria. Retrieved (05/ 2015) from: <http://uir.unisa.ac.za/handle/10500/4245>

- Thomas, R., Kuruville, S., Hinton, R., Jensen, S., Magar, V. & Bustreo, F. (2015) Assessing the Impact of a Human Rights-Based. *Health and Human Rights Journal*, 2(17), 11- 20.
- Tunali, B. & Power, T.G. (2002) Coping by Redefinition: Cognitive Appraisals in Mothers of Children with Autism and Children without Autism. *Journal of Autism and Developmental Disorder*, 32(1), 25-34.
- Turner, M. (1999) Annotation: Repetitive Behavior in Autism: A Review of Psychological Research. *The Journal of Child Psychology and Psychiatry*, 40(6), 839-849.
- UNICEF (2011) *The State of the World's Children: Adolescence Age of Opportunity*. Retrieved (11/2014) from:
https://www.unicef.org/adolescence/files/SOWC_2011_Main_Report_EN_02092011.pdf
- UNICEF (2014) *Convention on the Rights of the Child*. Retrieved (04/ 2017) from:
https://www.unicef.org/crc/index_30160.html
- United Nations (2006) *Convention on the Rights of Persons with Disabilities (CRPD)*. Retrieved (04/2017) from:
<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
- Varma, A. & Iskandar, J. W. (2014) Challenges in Diagnosis of Autism and the Struggle of Using Western Screening Tools in Different Cultures: Psychiatrist's Perspective. *Indian Paediatrics*, 51.
- Venter, A., Lord, C., & Schopler, E. (1992) A follow-up Study of High-Functioning Autistic Children. *Journal of Child Psychology and Psychiatry*, 33(3), 489-507.
- Vivanti¹, G., Barbaro, J., Hudry, K., Dissanayake, C. & Prior¹, M. (2013) Intellectual Development in Autism Spectrum Disorders: New Insights from Longitudinal Studies. *Frontiers in Human Neuroscience*. Retrieved (03/ 2016) from:
<http://journal.frontiersin.org/article/10.3389/fnhum.2013.00354/full>
- Walker, M. & Unterhalter, E. (2007) *Amartya Sen's Capability Approach and Social Justice in Education*. New York: Palgrave Macmillan Publisher.
- Wall, K. (2007) *Education and Care for Adolescents and Adults with Autism*. London: SAGE Publications Ltd.
- Weiss, M. J. (2002) Hardiness and Social Support as Predictors of Stress in Mothers of Typical Children, Children with Autism, and Children with Mental Retardation. *Journal of Autism*.

- Weiss, M. J., Robinson, S., Funga, S., Tinta, A., Chalmers, P. & Lunsby, Y. (2013) Family Hardiness, Social Support, and Self-Efficacy in Mothers of Individuals with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders*, 7(11), 1310-1317.
- White, N. & Hasting, R. P. (2004) Social and Professional Support for Parents of Adolescents with Severe Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 17(3), 181-190.
- Whiteley, P., Shattock, P., Knivsberg, A., Seim, A., Reichelt, K. L., Todd, L., Carr, K. & Hooper, M. (2012) Gluten- and Casein-Free Dietary Intervention for Autism Spectrum Conditions. *Frontiers in Human Neuroscience*, 6(344).
- Wiley, S., Gustafson, S. & Rozniak, J. (2014) Needs of Parents of Children Who Are Deaf/Hard of Hearing with Autism Spectrum Disorder. *Journal of Deaf Study and Deaf Education*, 19(1), 40-49.
- Wilkinson, K. & Twist, L. (2010) *Autism and Educational Assessment: UK Policy and Practice*. Slough: NFER.
- Woodman, A. C., Smith, L. E., Greenberg, J. S. & Mailick, M. R. (2014) Change in Autism Symptoms and Maladaptive Behaviour in Adolescence and Adulthood: The Role of Positive Family Processes. *Journal of Autism Developmental Disorder*, 45(1), 111-126.
- Worley, A. (2017) *10 Facts about Education in Bahrain*. Retrieved (04/ 2017) from: <https://borgenproject.org/education-in-bahrain/>
- Zuckerman, K. E., Lindly, O. J. & Sinche, B. K. (2015) Parental Concerns, Provider Response, and Timeliness of Autism Spectrum Disorder Diagnosis. *The Journal of Paediatrics*, 166(6), 1431-1439.
- Zukang, S. (2009) *The Role of Women in Development: Women's Control over Economic Resources and Access to Financial Resources, including Microfinance*. Retrieved (01/ 2017) from: <http://www.un.org/womenwatch/daw/public/WorldSurvey2009.pdf>

Appendix One
Mothers' stories in Saudi Arabia and
Bahrain

The Story of Nora in Saudi Arabia

‘There is nothing I can do to take his pain away. I am all alone. I am an orphan, both my parents are dead and I have no one to help me.’

Nora is a Saudi mother of six, one of whom is Ahmad, her 13 year-old son with autism. Nora had suffered many hardships, one of which is living with an unfaithful and unsupportive husband in a society that gives him unlimited power over her and her children. Since Nora does not have an education that allows her a decent job and guarantees her financial stability, she has no choice but to live with him. An argument in which he hit her led her to a divorce and Nora had to leave home to live with her brother and his family as both her parents are dead. After a few weeks, Nora had to come back for her children, especially Ahmad, who is fully dependent on her.

Though she decided to ignore her husband’s actions, and to focus on her children’s needs, Nora spends her days in despair. Her only income is from a small house her late father left her and her siblings, which they rent out dividing the money between them. Nora saves the money to buy her children new clothes for the festival season (Eid which happens at the end of Ramadan), and to pay for Ahmad’s needs. When Ahmad was born, Nora, as she described it, experienced one disappointment after another. She had no support from her husband. There was no appropriate Autism Centre and the health service was poor.

After visiting countless hospitals, Ahmad finally received a diagnosis of autism with severe intellectual disabilities. Once she had the diagnosis, Nora’s next stage of her journey was to find an affordable Autism Centre, someone to drive her and, with her husband’s permission, to enrol Ahmad into the centre. She managed to accomplish all that only when Ahmad was 10 years’ old. Further, because of the sex-segregated education system in Saudi Arabia, Ahmad could only stay in the Centre for two years until he was 12, when he had to be enrolled in all boys’ school. Nora enrolled Ahmad in a nearby public school that has classes for children with disabilities but no trained teachers of autism. In school, Ahmad was bullied, mistreated and hit by other children. With no access to her son’s school, and a father who took no interest in his son’s care, Nora felt helpless.

In Saudi Arabia, as I have discussed in the thesis, the household is headed by the husband or father. In Nora’s case, everything she does is controlled by her husband, including when she could get pregnant. When I interviewed her in July 2015, Nora’s issues had not been resolved and she was still struggling with financial problems, was fully responsible for Ahmad without any help or support, and living with an abusive and uncaring man. Nora

expressed emotions of sadness, despair and helplessness in her testimony, and was in tears during the interview.

The Story of Fatima in Saudi Arabia

'I have no choice but to take care of my children; their father left them. How can I also leave them?'

Fatima is a mother of three children with disabilities who comes from a very poor background. She has a 14-year-old boy with autism, a girl with severe intellectual disabilities and another with visual impairment. She managed to divorce her abusive husband who was unable to keep a job because of his bad behaviour. Yet he kept the children and prevented them from seeing their mother until they managed to run away and find their way back to her. Fatima works as a housekeeper in an all girls' college to support herself and her children since she is the only one who is fully responsible for them. With three disabled children and a minimum wage, Fatima struggles with crushing burdens. Her visually impaired daughter needs to visit a private ophthalmologist regularly and she needs a female companion to attend lectures with her at the university. Fatima is also paying a babysitter who takes care of her autistic son, Sameer, when she goes to work in the morning, as well as paying a driver who takes her to work and her daughter to university. While Fatima was living with her husband he prevented her from taking Sameer to the hospital. It was not until the divorce and the children came to live with her, when Sameer was 10, that she managed to obtain a diagnosis. However, no clear information was provided to Fatima about autism, or about the availability of disability centres. She had to search for this on her own, asking around since she cannot read or write. She eventually succeeded in enrolling Sameer in a state school, where he stayed for only one semester before she was asked to take him out because he was judged not to have the ability to learn. With the sex-segregated educational system, Fatima could not communicate with Sameer's teacher, and when she went to school in an attempt to talk to the supervisor, she waited outside in the heat for almost an hour then took a taxi home.

With no state Autism Centres, and no financial support, Fatima could not enrol Sameer in a private centre and, at the time of the interview, he had been staying at home. Also, Fatima is not entitled to enrol her children into schools without the signature of their father since he is the male guardian of the family. However, because she is in the process of getting Sak i'eala'a (a legal document granting women the right to be guardians of their children. See Chapter Six), the school accepted her older son's signature and she enrolled her children

into school. Despite the challenges Fatima confronts, she told me she was content and accepted her situation, believing that it is God's will for her and her children to live such a life.

The Story of Huda in Saudi Arabia (see the interview in Appendix Two)

'After they told me Ali has autism, I kept thinking why me? All my other children are normal, why this boy? What did I do wrong?'

Huda is a Saudi mother of six, one of whom is Ali, her 12-year-old son with autism. Ali's behaviour was difficult and neither Huda nor schools were able to handle it with the result that, whenever Huda enrolled him in a school, she was eventually told the school could not accommodate him. Huda finally received advice to take Ali to an Autism Centre for consultation where he was diagnosed with autism. However, the centre was unable to provide Huda with support, a place at the centre or adequate information about autism. Ali's behaviour was destructive and, without help or support, Huda resorted to violence as a means of unloading her frustration. She hit Ali every time he misbehaved. Finally, she decided to call the Autism Centre again to try and enrol her son, explaining to them that she was in desperate need of help and if they did not accept Ali she would end up hitting him until he died.

The Centre accepted Ali as a part time student and, at this stage, Huda did not really care if Ali would benefit from attending. All she cared about at the time was that someone take responsibility for caring for her son. Huda had no hopes for her son and for that reason she never followed up on his progress in the Centre. He was the helper's full responsibility with respect everything including his food, his clothes, and his studies. The centre asked Huda to meet with Ali's teacher and to her surprise his behaviour had improved. Her treatment towards Ali changed completely, and she became more caring and loving. Huda's husband plays a significant role in Ali's life, especially when Ali started attending the school where he works. The education Ali receives is inadequate. The school seems to be more interested in his mobile 'phone, leaving the students to do as they please. With no guidance and actual teaching Ali forgot all he had learned in the Autism Centre. Huda believes in Ali's potential and ability to learn but while Huda receives good informal support from her spouse and family, she struggles with formal support from the educational system.

The Story of Amal in Saudi Arabia

'It was my journey and Kareem's. Whenever his father helps us, he makes us feel like he is doing us a favour - like we did not deserve help or support, and he does it as a charity.'

Amal was a mother of two children until she lost her youngest son in a car accident, and was left with Kareem, her 19-year-old son with autism. Despite her social status and her above average financial situation, Amal struggles with her son's autism and lack of support, describing her journey with Kareem as lonely and painful. Kareem was misdiagnosed several times until he turned 10 when he was finally diagnosed with autism while Amal was studying in the UK.

Autism forced Amal and Kareem into isolation and Amal had to deal with the disorder on her own without the help of family or a spouse. The relationship between Kareem and his father is not a successful one, which makes him dependent on his mother for everything. Amal feeds him, bathes him, puts him to sleep, and so on. Kareem's behaviour had a negative impact on his late brother. While his brother would enjoy going out, Kareem would prefer to stay home and he hated meeting people. It was hard for Kareem's younger brother to cope with his brother's differences, which caused a separation within the family since Amal would spend her entire time taking care of Kareem's needs. Amal believes that Kareem's behaviour might have caused her other son to feel despair, and that the pain and lack of attention from his mother resulted in his accident.

Although Amal lives under the same rules as the other participants, she did not find it as difficult as the other mothers. For example, even though she did not have access to Kareem's school, she was able to bring his teachers to her house to discuss his case. Amal is well-connected and managed to get a special letter from the Minister of Education so that Kareem could take his final exams in a separate room. Yet despite her connections, Amal still struggles with loneliness and exhaustion. Not having a supportive spouse or an understanding family means she is the only care-taker of her adolescent son. Further, although her social status is above average, and she has the financial resources to provide financially for Kareem, Amal still worries about who will take care of him if something happens to her.

The Story of Noha in Saudi Arabia

'When I first heard that my son was suffering from autism, and that he will be like this for the rest of his life, I started crying. I was shocked that something like this even existed. Something called autism, and it is happening to my son.'

Noha is a Saudi mother of three, one of whom is Khalid, her 15-year-old son with autism. Even though Noha has a high school degree and does not have a job, her financial situation is above average because her husband is a businessman.

Khalid was immediately diagnosed with autism in one of the good hospitals in Jeddah but, after receiving the diagnosis, Noha felt confused and responded by reading about autism on her own to try to make sense of the disorder. Her husband was compassionate and understanding of Khalid's situation yet Noha is the sole carer for her son.

After the diagnosis she enrolled Khalid in an Autism Centre so he could benefit from an early intervention programme but, unfortunately, Khalid did not gain anything from this and so Noha and her husband considered sending him abroad. They heard about a Canadian boarding school in Egypt, and Noha and her husband visited the school before deciding it was a good place for Khalid to be. During the interview, Noha described the experience of Khalid studying abroad as positive. The school not only played a positive role in enhancing his skills, but also in dealing with his disorders, including an eating disorder and ADHD, which were managed using behavioural therapy.

After five years in the boarding school, Khalid was brought back to Saudi because of the political crisis in 2011. A new journey started for Noha and Khalid after his return from Egypt. Despite Noha's attempts to find Khalid a good Centre in Saudi, there were few good places, a lack of support, as well as a lack of leisure and entertainments such as gyms. Khalid loves swimming and has won many medals in the Saudi Special Olympics.

Although Noha was able to overcome mobility issues because of her ability to hire a driver, sex segregation was a distinct problem because Noha cannot take Khalid anywhere to swim or to exercise. These are men only places. Her husband, even though understanding, is not involved in Khalid's life very much. As a result, in the face of strict norms and conventions, Noha is powerless to provide her son with the simplest right to enjoy and practise his hobby.

The Story of Sarah in Saudi Arabia

'My son is intelligent, and I have plans to send him abroad for his university. Since he was little he liked to build Legos in a very unique way. I have a feeling he will grow into an amazing engineer.'

Sarah, is a Saudi mother of two, one of whom is Maher, her 13-year-old son with autism. Sarah works in a private university with a good reputation and which has Special Education Department which helped Sarah greatly. When Sarah described Maher's

symptoms to her colleagues she was told that he might have ADHD and so she started to read about it. However, Sarah always felt that what Maher had was more serious than ADHD, not least because of Maher's habits of playing video games continuously. Sarah tried to arrange a doctor's appointment but Maher will not willingly leave the house and doctors' appointments take a long time to make. Yet, she managed to make an appointment with the doctor when Maher was about seven years' old. The doctor asked her to make further appointments suspecting that Maher had autism. However, Sarah did not obtain an official diagnosis of autism until Maher was about 10 years' old when she made an appointment with the head of the Special Education Department in the university where she works. In the meantime, Sarah had read a lot about autism and compared what she read with Maher's behaviour. She also read about behaviour training and she used these methods to train Maher at home.

Sarah's husband was not supportive or helpful, and did everything on her own, such as reading about ASD and how to care for Maher. Sarah even believes that her husband is on the spectrum since he does not socialise with people, prefers isolation and does not like crowded places. Sarah also tried to explain Maher's disorder to her family and in-laws but they did not acknowledge his problem and her mother-in-law insists that Maher is not suffering from any problem.

Sarah placed Maher in a general school since he has no intellectual issues. Further, Sarah did not inform the school about Maher's condition since the school does not have classes for disabled children and she believed that, if they knew, they would not know how to handle him. In the beginning it was difficult for Maher to cope with his new environment, and other students used to bully him. However, Sarah enrolled him in Martial Arts training, which helped him gain confidence and start defending himself.

Sarah's situation is relatively good. She has the means to get the support she needs which makes it easier to overcome mobility restrictions. The university where she works provides her with the support she needs to understand her son's autism. Maher is a high functioning autistic person and that makes it easier for Sarah to care for him. During the interview, Sarah seemed at peace with Maher's condition, accepting his differences and focussing on the positive in his character.

The Story of Rasha in Saudi Arabia

'They do not care about the mothers in this country, they only care about the father - what family name your boy carries. To them, the mother does not exist.'

Rasha is a Saudi mother of nine, one of whom is Sami, her 13-year-old son with autism. Even though Rasha graduated from high school with the sixth highest grades in the entire western region of Saudi, and had a good chance to pursue her education, she was already married at this time and her husband did not allow her to go to college. Rasha struggles financially, which has a major impact on her ability to provide care for her son. Her husband has a modest job as a 'phone operator, and his pressing responsibilities to provide not only for his wife and children, but also for his mother, his older single sister and his widowed sister who has a child, make it even harder for Rasha to provide Sami with the financial support he needs. Because of this, Rasha could not enrol Sami in an Autism Centre, since all the centres she found were above her budget and she would have needed to pay for both tuition fees and transportation. When she managed to find a sponsor through the Autism Centre, someone willing to pay for Sami's fees, she claimed that the Centre used the money to pay for another child. Rasha also tried to gain government sponsorship for Sami, but she is still waiting for her husband to apply for that sponsorship since it has to be applied for by Sami's legal guardian, in this case his father. In addition to the difficulties with money, none of the hospitals Rasha visited with Sami seeking a diagnosis were helpful. On the contrary, one of the doctors performed an IQ test on Sami, and told Rasha, 'Your son is stupid, take him and go home'. She was then advised by one of her relatives to go to an Autism Centre and here she received Sami's diagnosis. As for the family support, only one of Rasha's sons is helping her with Sami and the rest of his siblings told her that whatever she is doing with him is useless and she should send him to a nursing home instead of wasting her time. With respect to her daughters, they both used to help with Sami but they are now married and busy with their own lives. Also, having reached adolescence and with a lack of schooling, Sami's condition is not getting easier, and Rasha has to handle many tantrums and outburst on her own. I witnessed these during my interview with Rasha.

With a lack of financial means and family support, Rasha's interview suggested that she suffers loneliness and feels oppressed. The role of male guardian plays a major part in Rasha's ability to provide care for Sami. She is not able to apply for the government's sponsorship on her own, she could not renew Sami's disability card to receive financial benefits, and she could not request any increase in benefits. Although, in most cases

mothers are the primary caregivers, they do not have the capacity to meet their children's needs because of constraints imposed by the norms and regulations of Saudi society. Moreover, with no support from the male members in the family, and the mother not allowed to drive, lack of mobility is also a struggle, since paying for transportation was the main reason for not enrolling Sami in one of the Autism Centres. According to Rasha, individuals with autism are forgotten in society and, without suitable and affordable Centres or schools to provide care and education, mothers are on their own without help or support.

The Story of Nada in Saudi Arabia

'When I was in the States, it felt like everyone was waiting for me to fall, including my husband. They were waiting for me to give up, to stop in the middle of the journey, pack everything and come back. I am the only one who supported myself, and gave myself the power to continue.'

Nada, is a Saudi mother of two, one of whom is Adel, her 12-year-old son with autism. Nada had a degree in psychology and was interested in autism even before her son was born. She started working in a well-known Autism Centre when her son was about four months old. In the Centre, Nada received detailed training on autism before she was allowed to work with the students. As Adel grew older, she started noticing some similarities between him and the children in the Centre such as his lack of eye contact, crying for no obvious reason, and unusual ways of playing with toys. Nada shared her doubts with her husband and her family, but they accused her of being under the influence of working in the field of autism and of being suspicious for no good reason. As Adel grew older, the autism symptoms became more clear and Nada finally managed to receive a diagnosis of autism, when Adel was four years old, in which the doctor only confirmed what she already knew. After that, Nada went to the United States with both her sons to study for a Master's degree in autism. She faced huge problems with everyone not wanting her to go to the States, since she was going alone with the boys, and her husband was staying in Saudi because of his job. Nada's in-laws were particularly opposed to her studying abroad and, even though her husband was supportive of her decision, he was influenced by his family and would, for instance, frequently 'phone Nada while she was in the USA and ask her to bring the boys and come home. Yet, Nada did not blame him for his behaviour since, according to her, he was under a lot of pressure, not just from his family, but also because of the customs and traditions of society.

Nada compares the schools in the USA and those in Saudi with disappointment. In the USA Adel was in a state school in which children with autism were integrated with more 'typical' children, and in which Adel was provided with a shadow, a support, teacher who explained to his friends in school his condition and how to best treat him. Nada described the three years she spent in the USA as the best years of her life, especially with respect to Adel's education, since she did not have to worry about anyone mistreating or bullying him. When they returned to Saudi it was a different story. Adel's condition is not severe, so Nada enrolled him in a private school but here he suffered mistreatment not only from other students, but also from teachers. The school is not supportive of Adel's condition and due to the sex-segregated system she is not allowed into her son's school. All she can do is to push her husband to go and check on Adel from time to time. Also, Nada, now as a Principal of an Autism Centre, has experienced the suffering and the agony of other mothers. She always advises them, if they have the financial capacity, to take their children and travel to a better place where their sons can receive a better education. Nada described, during the interview, not only an unsupportive education system but also a judgemental society. In the USA people treated her and Adel as 'normal' but in Saudi they are mostly met with looks of pity and sorrow, as if a mother of a child with autism, according to Nada, is not allowed to look happy or at peace but rather in continuous sadness and agony.

The Story of Mai in Saudi Arabia

'Rami's father does not talk much about his condition, and he does not share it with other people. It is as if he is ashamed of him. He never said it openly, but all his actions towards Rami scream shame.'

Mai, is a Jordanian mother of five, living in Saudi Arabia, one of whom is Rami, her 19-year-old son with autism. Rami was first misdiagnosed with intellectual disability and spent about a year in a disability centre, where Rami has gotten worse because of the mixed up disabilities and lack of qualified teachers. Then Mai decided to take Rami out and had a meeting with the centre's Principal, explaining the situation and sharing her concerns that Rami might suffers something else, in which the Principal advised Mai to take him to an Autism Centre. Mai managed to take him to the centre where he was diagnosed with autism and became a student in the same centre. One of the reasons Mai settled for the misdiagnosis was her unsupportive husband, when Rami was diagnosed with intellectual disability, she wanted to seek a different opinion but her husband being

impatient and short tempered refused to go see other doctors. He was not even convinced that education would help Rami, and only because of the help of friends who talked to him, he then agreed to send Rami to the disability centre. Mai's husband continued to be unsupportive, in which Mai used to attend parents' meeting on her own, being a private centre, Rami's father was allowed to attend such meetings. When Sami grow older and was transferred into the male department, Mai lost the access to her son, and her husband would not go and check on Rami's progress. As for Rami's siblings, at the beginning they used to treat him as a mad child, but then Mai used to take them with her to the centre to attend workshops about autism, so they understood their brother and started treating him better. After that, the male department in the autism was closed down, since the Autism Centre was part of a women charitable organisation, men were not allowed to be part of it even in a separate department. As a result, Rami has been staying home for the last year and a half and until the time of this interview. According to Mai, there are no specialised centres in autism, especially after the age of 12, which is the age boys are allowed in the women department, and the available centres are very expensive with no real benefits to offer. Society has no interest in autism, there are no real service available for the children and the mothers end up suffering on their own without help or support.

The Story of Rana in Saudi Arabia

'When Zaid was diagnosed, I felt like the person who lost everything. Both my boys have autism, and there is no difference in age between them. I had barely woken up from my first shock, to start going through another.'

Rana is a Saudi mother of four, two of whom are Yazeed and Zaid, 15 and 13 year old boys with autism. Rana is a pre-school teacher, who works in a different city, away from her family, since lately in Saudi Arabia most of recently employed teachers are assigned to schools in faraway cities since they lack qualified teachers in such remote areas. Since the start, Rana has been trying to get a transfer to Makkah, where her family lives, but at the time of this interview she had been unsuccessful. Rana came across autism while searching online about Yazeed's behaviour and, with the similarities she found, she became convinced that her son had autism. Rana managed to get an official diagnosis when Yazeed was about 3 years old. When Zaid was born, Rana noticed his distinctive behaviour immediately, and when he reached one year old, she was sure he also had autism. But this time she took Zaid to the Autism Centre his brother attends and, after few sessions with the specialist, Rana's suspicion was confirmed.

Rana's husband is a close minded man and when they first got engaged he expressed his wish that he wanted only to have boys, he did not want daughters. So, when his second child was born a boy, he was far happier than when his first daughter was born. When Rana first shared her worries that Yazeed had autism, her husband was furious with her. He called her mad and he did not fully accept his son's condition until Yazeed turned five years old. After that he distanced himself from his son, and Rana became fully responsible for him. When Rana started her job and left the house, her oldest daughter with the assistance of a helper, would take care of her brothers, and their father sometimes offered a little help. However, when Zaid was also born with autism, the father's frustration became stronger and he started talking about having a second wife to give him the healthy son he always wanted. He also talks about finding Yazeed a wife so that Yazeed can have a son who would help take care of him. When Rana argues with her husband that no woman would agree to marry Yazeed and that he has no idea what to do with a wife, her husband replies that Yazeed will learn what to do on his own and that they can always find a girl from a poor family from either Egypt or Morocco who would agree to marry him. As for the school situation, both boys are in a state school for children of all disabilities, with no special classes or qualified teachers to deal with autism. Both boys were previously in the same Autism Centre as Rami, Mai's son, but like Rami they had to leave when they closed the male department. Yazeed and Zaid are not receiving what Rana describes as any real care or education in their current school but Rana has no other option. The unsupportive husband, along with her job situation, makes things harder for Rana than dealing with autism alone. She cried a couple of times during the interview and talked of lack of support, the strain of dealing with autism, and feeling responsible for her sons' disorder. She is under an enormous amount of stress, which has led to high blood pressure and irritable bowel syndrome.

Mothers' stories in Bahrain

The Story of Asma'a in Bahrain

'We see everyone the same way; it is hard for our society to understand what is different from what they are used to.'

Asma'a is a Bahraini mother of two, one of whom is Khan, her 20-year-old son with autism. Asama'a is an English teacher and a great reader, but she had never heard of autism until she came across a television interview with a doctor who was talking about autism and then she linked it to her son's symptoms. Asma'a believes that autism did affect Khan's desire to be emotionally close to his family as he likes to hug them and kiss them, and feels happy to be around them. After the diagnosis, Asma'a started reading about autism to try to find the best ways to help Khan. She found out about the 'food diet' and put Khan on this in 2000 so that, she said, Khan knows what to eat and what not to eat. Asma'a has a supportive husband and a supportive family who helped her through her journey with Khan in addition to her support group that she helped to create. She was one of the founders of this parents' support group in Bahrain and they meet to discuss the best ways to deal with autism and support new mothers dealing with the disorder. Although Khan is mostly independent, he needs help with certain things such as showering and shaving. His father helps him with this and also taught him how to shave his sensitive areas. Asma'a trained Khan, from an early age, to clean his room, be organised and she said that she has taught him the sense of privacy. So, she did said she had not encountered any problems when he reached the adolescent stage and whenever he feels like touching himself, he goes to the toilet or to his room.

Asma'a also talked of her positive experiences with the Autism Centre, in which she and Khan learned a lot. The only issue Asma'a talks of facing is from society, especially because, she says, autism is a 'hidden disability'. For example, when she takes Khan to the park and he starts playing with little children, people start staring at him. Similarly, when she takes him to play in the shopping malls, he does not take turns with other children when he is playing with his favourite toys and, since he is non-verbal, he does not reply when people try to talk to him. Asma'a expressed her feelings of hurt because of the way people look at Khan and make comments about him. However, she also said that this never made her feel ashamed of him. She takes him with her everywhere and does not hide the fact that he has autism. What Asma'a wishes for is that individuals with autism have a more secure future in which jobs could be offered to them so they could feel useful, be productive members of their society, and earn and learn to support themselves.

The Story of Sana'a in Bahrain

'My husband was always with me - may Allah keep him safe for me and the kids. He is the one who went everywhere with me, helping me understand Saleem's condition.'

Sana'a is a Bahraini mother of five, one of whom is Saleem, her 16-year-old son with autism. Sana'a had felt something was wrong with her son since the day he was born. Sana'a is also a reader and knew about autism before Saleem was diagnosed. As he grew older, she started comparing his behaviour to what she read and she thought he might have autism. The hospitals disappointed Sana'a because they delayed Saleem's diagnosis until he turned three years old, even though Sana'a had taken him to many doctors. They had all insisted that there was nothing wrong with him. Sana'a struggled after this with the symptoms of autism because Saleem was hyperactive and hard to control. So it was difficult for her to take him to places because she feared that something bad might happen to him if she did not pay attention to him all the time.

Sana'a also expressed her worries about her son's sexuality and she had noticed that Saleem had reached puberty from his dirty underwear. Sana'a did not explain to Saleem anything about sexual behaviour or puberty, and she said that she hoped that her son did and would not experience any sexual desires. If he did she said she would not be able to help him control such desires.

Sana'a has a supportive family and a supportive husband who always helped her on her journey with autism. As for Sana'a's experience with the Autism Centre, Saleem is in a good Centre now but Sana'a is worried that when it is time for her son to leave the Centre, she might not be able to find another good place in which to enrol him. She does not leave him alone with anyone, such as a helper, not least because Saleem is nonverbal and Sana'a is fearful that they might take advantage of him. Just like Asma'a, Sana'a talks of struggling with society. As Sana'a described it, peoples' comments about Saleem used to annoy her but they do not any more. However, still she does not take him to many places because she does not want him to be hurt by others' comments. He is also very active and runs fast and she cannot catch up with him and so she worries he might get hurt. Sana'a is uncertain about Saleem's future, which is another source of worry. She hopes that someone will always be there to take care of him but, as she says, she cannot predict the future.

The Story of Samia in Bahrain

'When you have children with disabilities you move in a vicious circle. You are always looking for someone who has the patience and the ability to provide care.'

Samia is a Lebanese woman living in Bahrain, and a mother of two adolescents with disabilities. Fahad, her 15-year-old son has autism and Yara, her 18-year-old daughter, has an intellectual disability. Samia used to live in Saudi Arabia, since her husband worked there. However, due to the lack of good Autism Centres and issues with mobility and sex-segregation, they moved to Bahrain and her husband commutes every day to his work in Saudi. Samia noticed Fahad's different behaviour from the age of seven months. He used to look into a corner when feeding and there was a lack of spontaneous smiles and interactions with her and her husband. Samia took Fahad to a doctor but was told that everything was fine. She then heard about autism in television interviews and linked it to her son's behaviour before she obtained a diagnosis when Fahad turned two years old. By then, Samia had already experienced the issues of diagnosis and the search for schools and Centres with her oldest daughter Yara, so she now went through the same challenges with Fahad.

According to Samia's experience, interventions do not vary much whether a child has autism or an intellectual disability, and she and her husband had to go through everything for both children, including occupational therapy, physical therapy and speech therapy and this consumed the family financially. To provide such therapies and services for two children, said Samia, requires a large budget and this is not always easy. However, because of her husband's job, their financial situation is relatively good and they are managing to provide their children with what they need. They have two nannies, who Samia sent to the Autism Centre to receive special training for three months before they started to look after her children.

As for the adolescent stage, Fahad has reached puberty but Yara has not and Samia is planning to stop her menstruation using a surgical option after consulting a doctor. Samia has a supportive husband and during the interview she called him her 'pillar'. However, Samia said she tries to expose him to the minimum of the challenges and she only shares the absolutely necessary details with him about the children because of his demanding job and his own health issues which include high blood pressure and a heart condition. Samia did not have a good experience with hospitals and, even though she took her children to seek a diagnosis and support at an early age, she said that the doctors had not helped her. As for an Autism Centre, both children go to the same Centre and Samia said

that she was really happy about their education. However, she is worried about what might happen to them when they have to leave because they are too old to attend a Centre. By contrast with most of my participants, Samia's experience with society is positive. She said that she feels home in Bahrain and, according to her, society's awareness and understanding of autism is increasing and Bahraini people are really supportive and friendly in comparison with the society in Lebanon. Samia realises that both her children are severe cases and she thinks that they will never be fully integrated in society and that they will always need constant attention. Her wish for them is to have a place that can offer them a simple job that makes them feel good about themselves and helps them to be productive members of their society.

The Story of Noor in Bahrain

'Me as Noor, completely changed after Waleed was diagnosed with autism. I used to be without cares and to live my life without any stress at all. I actually surprised myself after my son was diagnosed. I decided to know everything about autism, and learn how to make my son feel better.'

Noor is a Bahraini mother of three, one of whom is Waleed, her 12-year-old son with autism. When her son was about five months old, Noor took him to the doctor because he would not response to his name by turning his head. The doctor at this time asked her to wait since this might be a hearing issue which would resolve with time. However, Waleed's 'different' behaviour was getting worse with time, so Noor's aunt suggested she take him to an Autism Centre for consultation and he was immediately diagnosed with autism. Although Noor had heard about autism before, she did not connect her son's symptoms to the disorder.

After the diagnosis, Noor started educating herself about autism by reading books, attending lectures and workshops. Even though she could not enrol her son in the Autism Centre at that time because of the long waiting list, she started attending workshops offered by the same Centre on how to deal with autism. As for the adolescent stage, even though Waleed had not reached puberty, he is aware of it and has told his mother that, in a year's time, he will become a teenager.

Although Noor's husband is a doctor in the military, and was away on a mission when the diagnosis was made, Noor considers herself lucky with respect to his support and her family's support. Her husband supports her decisions regarding Waleed and cares for her comfort by suggesting she leaves Waleed with her family and takes a break by travelling.

Although her initial experience with the doctor who suspected hearing issues and asked Noor to wait was negative, she said that she has had positive experience since this. After Waleed was diagnosed with autism at the Centre, they gave Noor information about a hospital where she should go for an official diagnosis. The hospital was well equipped and the team there took about a week to reach the final diagnosis.

As for society then, according to Noor, awareness and understanding are increasing, and she did not feel that the society was negatively judgmental about her son's condition. As for Waleed's future, Noor believe that her son has the ability to pursue university studies and obtain a degree. Noor also believes that mothers should also change the way they think about their sons if they are autistic. She thinks they should be more positive and believe more in their children.

The Story of Maha in Bahrain

'With no man to watch my back, and with the financial issues, people think it is easy to take advantage of me. At times, it feels like people are waiting for me to fall but I won't give this chance to anyone. I will keep taking care of my son and do whatever is necessary to give him the proper life he deserves'.

Maha is a Bahraini mother of one, Amir, her 15-year-old son with autism. Amir's behaviour started to change when he turned a year and an half and when, for example, he stopped speaking, started to fear people and became hyperactive. Maha took him to many hospitals where she was told that Amir was fine. It was not until he turned four years' old, when she took him to Jordan, that Amir was diagnosed with autism. Maha had had her doubts though, and since Amir's behaviour had started to change, she had started reading about different disabilities and visited disability centres in Bahrain seeking information. During her reading, she came across autism and linked it to Amir's behaviour but because the doctors had assured her that Amir was fine, she had doubted herself. After the diagnosis and Maha's return to Bahrain, she said that her entire life changed and she started to educate herself about the disorder in order to best care for her son. Maha also left her university, not least because a doctor in Bahrain had told her that she needed to choose between her education or her son because she would not be able to do both. She chose her son. After that, she managed to enrol Amir in a good Autism Centre. However, and because he developed epilepsy, his condition worsened. After that, the Autism Centre supported her to fund-raise enough money to take Amir to Italy for epilepsy treatment. Amir felt better and they returned to Bahrain but six months later, Amir's condition started

to deteriorate and Maha took him back to Italy. To collect enough money for the second trip was, according to Maha, a 'miracle'. Maha and Amir participated at that time in Bahrain Independence Day celebrations in which thousands of people stand in the street to cheer for the Prime Minister. Amir was in a wheelchair at that time because of his continues seizures and Maha feared that he might have a seizure, fall and hurt himself. The Prime Minister saw them and sent his guard to ask Maha and Amir to come meet him, and he asked why Amir was in a wheelchair. Maha felt this was a good opportunity to discuss Amir's case and to ask for the Prime Minister's help. The next day, Maha was contacted and told that Amir's expenses would be taken care of and that applied anywhere in the world. As a result, Amir's entire expenses have been covered since 2007 when they returned to in Italy and then in Jordan after that. After Italy, Maha took Amir back to Jordan and the doctor suggested it would be best for him to attend a boarding school in which he remains at the time of my interview.

As for Maha's ex-husband, he blamed her for Amir's condition and did not accept Amir as part of his life after the diagnosis. However, Maha said that her divorce from him then made her stronger and increased her capacity to care for her son. Maha sees her son getting better in the future, and she believes that they will be both rewarded in heaven and in the afterlife for their struggles.

The Story of Warda in Bahrain

'I say to my daughter, I made sacrifices and sent Taher to Jordan so she can study, and her little brother can be safe and her father can work. Yes, I am devoted to Taher but they are different.'

Warda is a Bahraini mother of three, one of whom is Taher, her 14-year-old son with autism. Like Maha, Warda gave up her work, for her in a restaurant where she was working as a chef, to take care of her son and she is Taher's primary carer with full responsibility for him. Similar to Maha's story, Warda's son's behaviour started to change when he turned a year and one month. He lost his ability to speak, lost eye contact and became hyperactive. Warda also struggled with the hospitals in Bahrain. She took Taher to many doctors and they all said that there was nothing wrong with him and that Warda was imagining things. As a result, Warda took Taher to Kuwait where he received an official diagnosis of autism.

After Warda's return, she started driving around in Bahrain looking for a suitable place for Taher, but this was a struggle. First she enrolled him in a disability centre, but they did

know how to handle him. After that she enrolled him in a private school and they also failed until, finally, Warda managed to find a Centre specialised in autism. However, Taher developed a running away behaviour and ran away from the Centre and from his home several times which made Warda really worried about him. During that time, she took him to Jordan for Hyperbaric Oxygen Therapy (HBOT) and left him there for three months. After that, Taher started having migraines which run in the family, and because of the continuous headaches, Taher became violent and aggressive towards himself and others. He also developed epilepsy and, whenever he gets a headache, he starts hitting his mother, perhaps, she said, as a way of expressing his pain. Warda had to take him back to Jordan and enrolled him in a boarding school because he needed continuous care.

Warda's husband is completely withdrawn from Taher's life and, according to Warda, he has no idea how to deal with him. As for Taher's expenses, Warda tried to have the government sponsor part of Taher's education. However, she was told that they do not sponsor children with autism because it is a lifelong disorder without a cure. She also met with the Bahraini Ambassador in Jordan but, instead of offering help, he suggested asking the Prime Minister for help. His response shocked Warda and she told me that she had replied: *'This is a street fight! Where are the rules and the regulations? What is the role of the Ministry of Social Development and the Ministry of Education?'*

Although Taher is in Jordan, Warda still volunteers with the Autism Centre when needed to offer support and help to new mothers of children with autism. What worried Warda the most about Taher's future is where he would go if the boarding school asks her to take him out when he reaches a certain age.

The Story of Nouf in Bahrain

'I will never forget the day Sultan was diagnosed. Although I was sure Sultan was suffering from a problem, I still had hope that I was mistaken until the day when the doctor threw the diagnosis at me without any consideration of the way I feel.'

Nouf is a Bahraini mother of four, one of whom is Sultan, her 16-year-old son with autism. Similar to Maha and Warda, Nouf struggled with the hospitals in Bahrain and after many visits to different doctors in Bahrain, all assuring her that Sultan was fine, she took him to Kuwait where he received his official diagnosis of autism. After the diagnosis, Nouf took Sultan to Jordan and, again, the doctors advised her to leave him in a boarding school. She did this for about a year but, thinking he was making no progress, she then decided to bring him back to Bahrain.

According to Nouf, Sultan missed any early intervention because there was not a good centre in Bahrain, and it was not until an Autism Centre opened that she managed to enrol him and learned a lot and became better. Her fear, though, is that Sultan is growing up and that, soon, he will have to leave the centre. This, she said, would take her back to step one and she would need to start again to look for a place in which to enrol him. After reaching puberty, Sultan started showing sexual behaviour, and Nouf taught him a sense of privacy. So, whenever he feels sexually aroused, he goes to his room to masturbate knowing this is personal and no one should be around.

Nouf has a supportive husband and, during the interview, she talked often about how they depend on each other to care for Sultan. However, Nouf's family never bothered to help except with what she described as verbal rather than actual support. Nouf also believes that society lacks an awareness and understanding of autism and that, even though autism is, she said, increasing, people still do not know to handle individuals on the spectrum. Nouf's current struggle is where Sultan could go after he has to leave the Centre, especially as she is not planning to take him back to Jordan. However, she said she was hopeful that anything was possible and that God is able to change anything.

Appendix Two

Sample Interview Notes and Extracts: Huda, a Saudi Mother

Saudi Arabia (Makkah) face2face

Case	Name	Children	Adolescents with autism	Marital status	occupation
2	Huda	6	1 (boy) – Ali	Married	Religion teacher

The mother wanted to ask her husband for permission before allowing me to record the interview, but could not reach him so she agrees. I also assured her that no one will listen to the interview and the only reason I am recording because I will not be able to write everything she says immediately.

Personal information

Huda has a bachelor degree and works as a religion teacher in all girls' school. She has 6 children, 4 girls and 2 boys. One adolescent with autism – Ali (12 year old).

Financial situation

Both Huda and her husband work as schoolteachers.

Huda lives in a modest building in an old neighbourhood. Her husband owns the building so they do not pay rent. Children with disability receive benefits from the government depending on the type of the disability they have. In Ali's case, his father refuses to apply for the money saying that he has the financial ability to handle his son's expenses. Huda, on the other hand, tried to convince his father to apply even if they did not use the money, and to keep it aside as savings.

Huda said:

"We are not going to live forever. We should take this money and put it aside for Ali. If something happens to us, he has his own income and will not need anyone. I tried many times to discuss this with my husband but he always refuses the idea".

Diagnosis of autism

Huda started noticing issues with Ali when he was about 5 years' old. He likes to stay alone, does not play with other children, and does not realise the meaning of danger, as he would run in the streets in front of speeding cars. Ali was able to say some words such as "I want" or "I like" but then suddenly became mute. He has destructive behaviour; he breaks things and creates chaos. He was also very hyperactive and it was hard for the Huda to control him. At the beginning, Huda thought the reason behind his actions was his jealousy of his new-born sister.

Then a few of Huda's friends advised her to put him into a preschool so he would socialise with children his age which would eliminate his loneliness and improve his behaviour.

Huda enrolled Ali in three different preschools, but she was asked to take him out of every school because of his difficulties. Huda decided to enrol him in a private preschool.

Huda said:

“I knew how hard Ali’s behaviour was, and I told the preschool that I was willing to pay double the fees if they would keep him and not ask me to take him out”.

The principle of the private preschool noticed Ali’s different behaviour and thought that he might have ADHD, and suggested to Huda to take him to an Autism Centre for consultation. The principle told Huda that she did not mind accepting him in her preschool, but it would be better to make sure he was not suffering from serious issues.

Huda contacted the centre, booked an appointment, and went with her husband to see the specialist. The specialist conducted few tests and scales, then informed the parents that Ali had autism. Huda believed that the centre’s diagnosis was enough and did not take him to a hospital for a second opinion. When Huda’s son reached 9 years old, she took him to the hospital only to get an official report that he had autism.

Dealing with the autism symptoms

After receiving the diagnosis from the Autism Centre, Huda felt lost and started blaming herself for Ali’s condition.

She said:

“After what they told me about Ali, I kept thinking ‘why me? All my other children are normal, why this boy? What did I do wrong?’ I do not remember taking a wrong medicine during pregnancy or overtaking an x-ray!”

After the shock and the self-blaming phase, Huda started educating herself about autism. She started reading books and articles on the internet about the spectrum to try to understand Ali’s condition. Nevertheless, she was still not able to handle him on her own. Huda’s struggles with mixed emotions of helplessness, lack of support and her inability to enrol Ali into the Autism Centre. She resorted to violence as a means to unload her frustration. She started hitting Ali every time he misbehaved. One day, she decided to call the Autism Centre for another try to enrol her son.

Huda said:

“I called the centre and I talked to the specialist I met before and started crying, I told her that me and my son were in desperate need of help. I told her I did not know how to deal with him, and that if she did not accept him into the centre I was going to hit him till he died”.

The specialist asked for a week to try to arrange something for Ali. After that, the centre contacted Huda, asked her to bring Ali daily for only 2 hours on the condition that his mother or a house-maid should attend with him. With no alternative, Huda agreed to this arrangement.

Huda said:

“The amount of money the centre asked for was a lot for only 2 hours a day, but I did not care. Both my husband and I are teachers and willing to pay. All I wanted was for my son to go to the centre, and I sent the maid with him every day”.

At this stage, Huda did not really care if Ali benefited from attending the Autism Centre. All she cared about back then was for someone else to handle the responsibility.

She said:

“I did not know what to do with him on my own, which is why I wanted him to go to the centre. It did not matter to me if he learned or not, I just needed help. If he learns and improves that’s good, if he does not I will just put him in a room and lock him in”.

The mother had no hope for her son at that time which is why she never followed up on his progress in the centre. He was the helper’s full time responsibility - his food, his clothes, and studies.

Huda said:

“At that time I completely ignored my son like he did not even exist in my life. I always said to myself, ‘you have other children, take care of them; they are the ones worthy of your time’”.

Approximately a month later the Autism Centre contacted Huda to come and attend one of his sessions. Huda resisted the idea of being part of Ali’s life and almost refused to go, yet she made an appointment and went anyway. Watching Ali during his session was a big surprise for Huda.

She said:

“I did not believe my eyes when I saw Ali. He was well behaved, he recognised his desk, his bag, and he knocked on the door before going to class. He even knew how to hold a pen and write. After seeing that I held Ali tight and started crying”.

Huda’s treatment towards Ali changed completely after that visit. She started opening his school bag, and trained him at home. She started working hard with Ali, printing out worksheets from the internet and created a well-structured environment for him to learn. As for alternative medicine, Huda did not seek help. She also mentioned the autism diet, and how she tried it but could not continue with it.

She said:

“I was excited when I first heard about the autism diet, and I did follow it with Ali for a while. Yet it was hard because of his siblings. It would break my heart that he could see them eating what they wanted and he could not”.

Although Ali is 12 years’ old, Huda still feels guilty about him having autism. She asked questions such as whether autism is hereditary, and whether the painkillers she took during pregnancy could lead to autism.

Growing with the spectrum

When Ali reached adolescence he became more aggressive and very impatient. He fights a lot with his little sister. He also takes everything very personally at home and in school. Even when other students try to joke with him, he takes it very seriously and becomes extremely upset. He does the same at home.

Huda said:

“Ali becomes more sensitive as he grows older. When we talk at home and laugh, he thinks we are laughing at him and says to us ‘you are laughing at me and making fun of me’. He also finds it hard to mingle with other students at school for the same reason. He does not realise what jokes are”.

Ali also becomes more shy and quiet. He talks less, especially to his sisters and does not look at them. He is also scared of asking things from his mother thinking she is not going to approve although she encourages him to talk and ask. He also bursts into tears when she refuses to give him what he wants, and when she shouts at him, he accuses her of hating him.

It becomes harder to deal with Ali as he grows older.

Huda said

“He wants to be independent and wants to go out on his own but it was really hard for me to accept that. Usually his brother goes with him to the convenience store next door, but he wanted to go alone so his father taught him how to buy stuff and count the money and sent him on his own. I was very scared that day but he managed to go, buy the stuff and come back safe”.

Huda is happy Ali is a boy and not a girl and refused the idea of masturbation.

She said:

“I am so happy I have a boy with autism and not a girl. Dealing with the puberty would’ve been a nightmare. I know Ali might have reached puberty but I do not pay much attention

to these things. I only fear sexual assault because Ali could be an easy target for others. As for masturbation no way my son would do that”.

The spouse- support (informal support)

Huda’s husband did not take the diagnosis seriously at the beginning. During the phase of shock and self-blame, Huda felt completely alone with something she did not know or understand. She had to deal with the spectrum on her own without any help or support, which may explain her violence towards her son. The husband did not believe autism even existed and completely ignored the issue and called his son’s behaviour ‘kids misbehaving’. As time passed by the father became convinced about Ali’s situation. Later on, he played a big role in Ali’s life. When Ali started attending the school where his father works they become close. He would accompany his father every morning and come back together when the school day ended. Ali’s father takes care of him throughout the school day. For examples: Ali does not stand the morning queues, spends his break time with his father, and his father visits his class regularly to check on him.

Due to Ali’s case, the teachers started taking advantage of the father in order to treat Ali better. For example: when the father was asked by one of his colleagues to take his class, or switch classes he cannot refuse since his actions would affect Ali.

Huda said

“My husband does not complain but I can feel how stressed he is. Sometimes when he comes home late from school and he says he was covering for one of the teachers, I say to him ‘why do you accept?’ He replies smiling: ‘how can I refuse when he is teaching my son?’”.

The father also goes to prayers at the mosque and takes Ali with him, and talks to him about the importance of praying. Ali always asks his father to go pray with him and if his father is sleeping, he wakes him up to go to the mosque, which is another form of connection between Ali and his father.

Huda said:

“Ali is very close to his father now, even more than me. Yet his father does not believe that Ali needs special treatment. When I tried to get him a special educator at home he refused saying that Ali is studying at school and he does not need it”.

Family support- friends (informal support).

Ali’s siblings all care about him and understand his situation. They try to help their mother relax and calm her down when she gets nervous with Ali. His older brother, who is 15

years' old, helps his mother to take care of Ali. He teaches him and calms him down during his tantrums. Ali's older sister also used to help a lot, but she got married and moved to her own place.

Huda said:

"His older brother tried to help me a lot, but he cannot on his own. And with my daughter getting married and having children the family is getting bigger. It is hard to take care of Ali as before. I even forget about him sometimes when I'm busy with my other children and my grandchildren".

Hospital support (formal support).

The hospital had no role in Ali's case, since the diagnosis was done through the Autism Centre. Huda did not seek another opinion through medical staff. She only took Ali to the hospital to get a formal report to conform he had autism.

Institutional support (formal support).

Huda's first visit to an Autism Centre was to seek diagnosis for Ali, where she heard the word autism for the first time. The specialist tried to provide a simple definition when Huda asked what autism was by explaining it as a lack of communication with others, lack of social skills and lack of responses.

Huda said:

"I did not know what she was talking about. I tried to explain to her that my son responds to me when I call him at home. However, she replied that he is not focused, and there is a barrier between him and me. She also said, 'your son lives in his own world'".

Huda still did not fully understand ASD and her husband did not take the diagnosis seriously.

After that Huda asked about solutions for her son's autism. The centre explained to her that he needs special training; yet, they could not accept him because of too few spaces.

Although the Autism Centre was not supportive at the beginning, they managed to help Ali improved. Huda was impressed with such improvement, which lead to a better relationship with Ali. She regained hope in him and started his training at home. Due to the Autism Centre and Huda's work, Ali gained many skills and hugely improved in his studies. For example, he learned the alphabet, numbers and colours before the end of term. He also started talking and saying his name. As a result of his development, the Autism Centre agreed that Ali could attend full time. He showed talent in using computers and the perfect use of computer learning programmes. He won a national prize in using computers for children with special needs.

Huda said:

“We were very proud of Ali for his accomplishments. Even his father said: ‘Ali is the only son who gave me an opportunity to meet a prince from the royal family when he was handed his prize’”.

Ali spent three years in the Autism Centre, when they believed it was time for him to be integrated into public education. As a first step, and to prepare for the transfer, the centre started taking Ali on field trips to both public and private schools where they accept children with special needs. Unfortunately, Ali was rejected from one private school and three public schools due to his ADHD. The schools decided he would not be able to stay in the classroom during the lesson time because of his hyperactivity.

Such rejection left the parents with no option but to take Ali to a specialist public school in disability (Ma’ahd al-tarbiyah al-fikriyah). Ali stayed there for less than a month, until the teachers advised the father to take him out of the school. According to the teachers, the curriculum they offer was not suitable for Ali’s intelligence, which made his attendance useless. They suggested moving Ali to a general school, and asked his father to name the schools to which he wished Ali to transfer Ali, and since he is a teacher, he named his own school. Then (Ma’ahd al-tarbiyah al-fikriyah) contacted the school to explain Ali’s case and the best way to deal with him. The transfer was completed.

Ali started attending the school where his father works as a teacher. At the beginning, Ali received special treatment from other teachers as a complement to his father. After that, teachers started complaining about Ali’s skills and how hard it was to teach and deal with him, although (Ma’ahd al-tarbiyah al-fikriyah) send a specialist once every two months to check on Ali’s progress. No care was given to Ali. Whenever his father goes to check on him he sees that the teacher is busy with his mobile, leaving the students to do as they please. With no guidance and actual teaching as time passes, Ali forgets all he has learned in the Autism Centre.

Huda said”

“There is no reason for the teachers to help Ali or take care of him. There are no financial benefits to them. Teachers in (Ma’ahd al-tarbiyah al-fikriyah) are given extra salary since they are teaching children with special needs, unlike teachers in the general education. Therefore, no one cares about my son, and they only pass him because of his father. His books are untouched and he is not given any homework. I have no other choice in this matter; it is either that or he stays home and does nothing”.

Ali is faced with many difficulties attending the school. His teaching methods are the same as his typical classmates in a class of 37 students, with no special visual aids or specific curriculum that is suitable for autism. The teachers have no training to deal with the spectrum, despite the specialist's visits every two months. He is also being bullied by other students, making fun of the way he speaks, stealing his pens and his food, and on many occasions hitting him.

Huda said:

"I know my son is suffering. One time his father went to his class to check on him in a middle of a quiz. Everyone was writing except Ali, when his father asked him why he replied 'I do not have a pen'. The teacher did bother to even give him a pen or ask him to answer the questions. They just do not care".

She also said:

"Ali is older than his classmates. When they bully him or hit him and he defends himself by hitting back, he gets all the blame. Parents complain how an older kid is hitting their kids even though they are the ones bullying Ali. I teach him not to hit even if they hit him. I don't want him to be expelled from school as then he will have nowhere to go. There are no alternatives; our education system is very poor and all schools are the same. Also, I do not want to take Ali to an Autism Centre, at least he is in a school even if he is not benefiting from it. Taking him back to an Autism Centre feels like he is going back to ground zero".

For Huda it is better for Ali to be granted a certificate from a general school even if he is not learning anything than to send him to an Autism Centre where he can actually maintain his progress. It is also hard for her to send him abroad on his own, such as Jordan or Egypt, and cannot leave her family behind and travel with him.

Huda said:

"I got used to the idea that Ali goes to school and learns nothing but brings a certificate home at the end of every month. I do not know if we are laughing at the school or the school is laughing at us, but in both cases Ali will pass and graduate from the primary level".

Society

All mothers share the issue of mobility, since Saudi women are not allowed to drive. Huda used to pay a driver to take Ali to the Autism Centre then to (Ma'ahd al-tarbiyah al-fikriyah). Then he started going with his father once he moved schools.

Ali's sensitivity increased with age, and it is hard for him to understand humour which increased his tantrums, and that makes it more difficult to be around people.

Huda said:

"People around us now notice Ali's differences more than when he was little. His sensitivity is one of the biggest issues we are facing with him now, so we do not take him out with us when we go visit family members or when we go out. We are not ashamed of our son; we just do not want to put him in embarrassing situations. The hardest part, though, is when his relatives ask about him. We have to make excuses for him not being there. I think if I would've given Ali a choice, he'd rather stay home than come with us".

She also said:

"Our extended family is avoiding my daughters. They fear that autism is hereditary so no one would propose to them although my daughters are the best in the family, they are the only ones who are educated. Also my older sister has some mental problems, and I can sometimes see it in my husband's eyes that I am the reason why Ali has autism".

My Notes Immediately after Interview

Huda, even though educated, is still not aware of her and her son's rights. When she contacted the Autism Centre in the middle of her breakdown, she felt appreciative of their acceptance of Ali although they did charge a lot of money for a relatively small service. Not only had Huda to pay lots of money for two hours a day, she also had to send a helper to take care of Ali during these 2 hours.

Huda said:

"I cannot forget their favour when they agreed to accept my son. I was on the verge of a nervous breakdown and they saved me".

Huda as a mother of an adolescent with autism in my opinion is entitled to help and support. Guidance and services are supposed to be the Autism Centre's duty towards her and her son. Yet, Huda was sent home right after the centre informed her with the diagnosis without consideration to her situation, which I believe led to her mistreatment of Ali. She afterwards managed to seek help and enrolled Ali into the centre. His behaviour improved enormously after starting his training, which encouraged Huda to be cooperative with the centre and start training him at home.

After that, Ali and his parents were faced with one disappointment after another. The specialist disability schools rejected Ali claiming that he is too intelligent to be accepted,

while the general schools were unable to handle his disability. Such dilemma led to Ali's attendance in a general school where he is protected by his father.

As a high school teacher, Huda believes that the entire education system lacks utility.

She said:

“Teachers in schools do not care about typical students, so it is quite normal that they do not pay attention to students with disabilities. We as teachers are evaluated according to the passes and fails of our students. So most teachers care about how to make students pass even if they do not deserve it. This happens in the girls' school, so just imagine how would it be in boys' schools where many teachers care about their mobile 'phones and completely ignore their students”.

As for Ali, Huda believes in his potential and ability to learn, yet she sees these skills as useless since they are not being utilised in the real world.

She said:

“Ali is very good at learning new things. He is also very good at math and at using computers. But what is the point of him having these skills if they are not utilised? He is doing ok now in the primary level with the help of his father, but what is going to happen to him when he moves to high school? My son's future is uncertain and scary. His father and I are taking care of him now, but what if something happens to us? Who is going to be there for Ali?”

Huda is receiving good informal support from her spouse and her family, yet struggling with formal support given by the educational system. She is comfortable that Ali's father is taking care of him, yet she worries about his future. Although Ali's siblings are good to him, they will not take care of him as his parents do. In this case, the role of the state is completely marginalized where no support is given to the families in need. Huda wishes for a better formal support, where she expresses her desires to better schools, better Autism Centres and more attention and care for the children on the spectrum.

Huda said:

“I wish there were more attention given to autism from the government. All we need is a better education system, at least specialised and trained teachers in the general school and specialised classes for autism. What is the point of integration if they put my son in a 35 student classroom without paying any attention to him?”.

When Huda and I were discussing Ali's reaction towards society, she mentioned that he does not really mingle with other people because he does not join them in their outings. I did not ask her the reasons behind leaving Ali at home when the rest of the family goes out

yet I believe she sounds defensive when emphasising that they are not ashamed of Ali and he is left at home for his own good. Huda assumes that it is best for Ali to stay home, and it makes him happier not to see people or socialise with them. Nonetheless, she believes that going out is important for Ali and he should be socialising with others, especially that he is older. In my opinion, Huda's reaction is normal given how judgmental Saudi society is. In such a conservative culture, people are usually eager to feel accepted and having a child on the spectrum makes such acceptance even harder to obtain.

Finally, Huda believes that no one will take care of Ali if something happens to her, and uses her older sister as an example. After her mother passed away, no one helped her sister, even Huda herself gets busy with life and cannot be there for her own sister.

Huda said:

"Sometimes I pray to God that Ali dies before me, because I know no one will take care of him like I do".

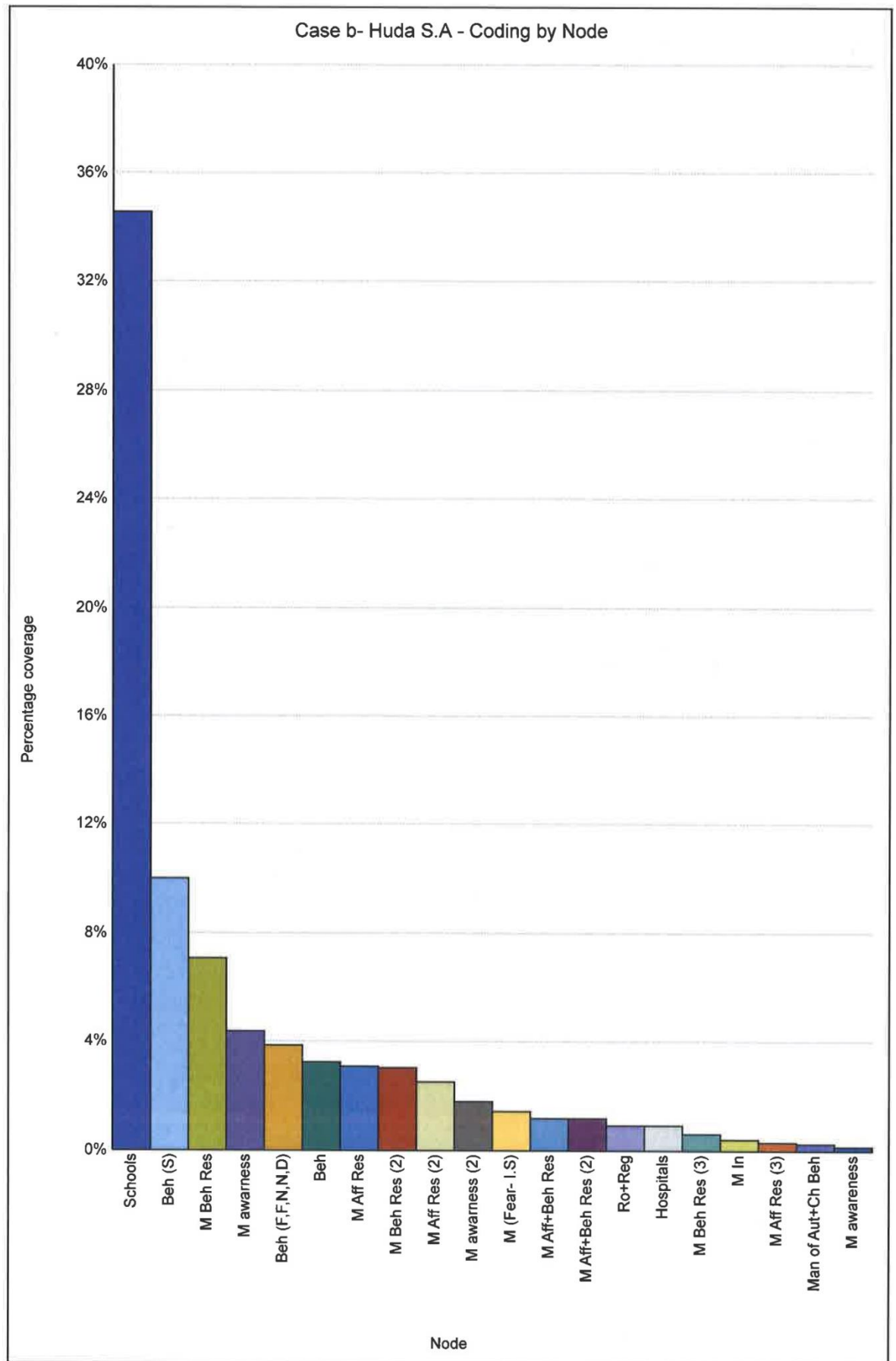


Chart key

M= Mother

Beh= Behaviour

Res= Responses

F= Family

F= Friends

N= Neighbour

N= Nanny

Aff= Affective

S= Spouse

I.S.= Ideal Situation

Ro= Roles

Reg= Regulations

Man= Manifestation

Aut= Autism

Ch= Child

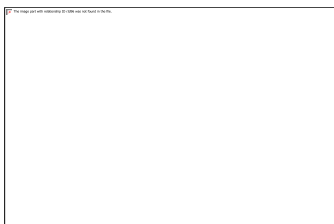
In= Interpretation

D= Driver

Att= Attitude

Appendix Three
Plain Language Statement

THIS FORM WILL BE TRANSLATED INTO ARABIC



Plain Language Statement (or Participant Information Sheet)

Study Title and Researcher Details

Social support for mothers of adolescents with autism in Bahrain and Saudi Arabia.

Researcher: Wid Hussain Daghistani w.daghustani.1@research.gla.ac.uk

Invitation paragraph

You are being invited to take part in a research study. Before you decide whether to take part, it is important for you to understand why the research is taking place, and what it will involve. Please take your time to read the following information carefully and discuss it with others if you wish. Also, do feel free to ask me any question if things are not clear or if you require more information.

Thank you for your time.

What is the purpose of the study?

I am a PhD student in the School of Education at the University of Glasgow. The main purpose of the study is to explore social support for mothers of adolescents with autism in Bahrain and Saudi Arabia. Adolescents in this study are young people between the ages of 12 and 21.

Why have I been chosen?

You have been selected to take part because you are a mother of an adolescent with autism and you live in either Bahrain or Saudi Arabia.

Do I have to take part?

It is up to you to decide whether or not to take part in the study. If you decide to take part, you are still free to withdraw at any time and without giving any reason. If you decide to withdraw, the data you have provided will not be used in the study unless you wish it to be included.

What will happen to me if I take part?

If you agree to take part in this research, you will be invited to take part in an interview, either face-to-face or by Skype. The interview will take place at a time convenient to you. Face-to-face interviews will be conducted in a private room in an Autism Centre office. If you choose to be interviewed over Skype, I shall ask you to ensure that you can Skype in privacy for the duration of the interview. The interview will take approximately sixty and no more than ninety minutes and will be recorded, with your permission, on a digital audio device.

Following completion of the interview, I will email a copy of the interview transcription to you. If you feel that the transcript manuscript misrepresents any of your ideas or words you may ask to make amendments, deductions or additions to your discussion.

I may ask for a follow-up interview with you, of no longer than 30 minutes.

Will my taking part in this study be kept confidential?

All information collected about you during the course of the research will be kept strictly confidential. You will be identified by an ID number and any information about you will have your name and address removed so that you cannot be identified.

Only my supervisors and I will have access to the audio tapes, text files and transcriptions of the interviews. The tapes and transcriptions will be given an identification code rather than being labelled by name. When the findings are written up, all quotes will be identified by a pseudonym and all other identifying details will be removed. The destruction of the audio recordings and transcripts will be completed after successful examination of my PhD.

All data from the study will be stored in a password protected computer and USB device. The PhD or future publications arising from the research will not identify you personally or include any identifying information.

What will happen to the results of the research study?

The results of the research will be used to complete a PhD thesis, and may be used for conference papers and publications, and to inform teaching practice. Upon completion of the research, a summary of the results will be provided to you.

Who is organising and funding the research? (If relevant)

The research is funded by a scholarship from the Arabian Gulf University in Bahrain.

Who has reviewed the study?

The project has been reviewed by both my supervisors, Professor Nicki Hedge and Dr Alison Mackenzie, as well as by the College of Social Sciences Research Ethics Committee.

Professor Nicki Hedge Nicki.Hedge@glasgow.ac.uk

Dr. Alison Mackenzie Alison.Mackenzie.2@glasgow.ac.uk

Contact for Further Information

My contact details and those of my two supervisors are provided. If you have any concerns regarding the conduct of the research project do not hesitate to contact the College of Social Sciences Ethics Officer **Dr Muir Houston**, at: Muir.Houston@glasgow.ac.uk

Appendix Four

Nussbaum's List of the Ten Central Human Capabilities

The Central Human Capabilities

The Capability Approach does not only focus on what individuals see as satisfying but rather on what they are capable of doing and being especially when given the right and needed resources within their society. Where a just society according to Nussbaum should provide its citizens with ‘some appropriate threshold level’ (Nussbaum, 2006, p.75) of the following ten capabilities:

1. Life. Being able to live to the end of a human life of normal length; not dying prematurely, or before one’s life is so reduced as to be not worth living.
2. Bodily health. Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter.
3. Bodily integrity. Being able to move freely from place to place; to be secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction.
4. Senses, imagination, and thought. Being able to use the senses, to imagine, think, and reason- and to do these things in a “truly human” way, a way informed and cultivated by an adequate education, including, but by no means limited to, literacy and basic mathematical and scientific training. Being able to use imagination and thought in connection with experiencing and producing works of events of one’s own choice, religious, literary, musical, and so forth. Being able to use one’s mind in ways protected by guarantees of freedom of expression with respect to both political and artistic speech, freedom of religious exercise. Being able to have pleasure experiences and to avoid non-beneficial pain.
5. Emotions. Being able to have attachments to things and people outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to love, to grieve, to experience longing, gratitude, and justified anger. Not having one’s emotional development blighted by fear and anxiety. (Supporting this capability means supporting forms of human association that can be shown to be crucial to their development.)
6. Practical reason. Being able to form a conception of the good and to engage in critical reflection about the planning of one’s life. (This entails protection for the liberty of conscience and religious observance.)
7. Affiliation.
 - A. Being able to live towards each other, to recognise and show concern for other human beings, to engage in various forms of social interaction; to be able to

imagine the situation of another. (Protecting this capability means protecting institutions that constitute and nourish such forms of affiliation, and also protecting the freedom of assembly and political speech.)

- B. Having the social basis of self-respect and non-humiliation; being able to be treated as dignified being whose worth is equal to that of others. This entitles provisions of non-discrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion, national origin.
- 8. Other species. Being able to live with concern for and in relation to animals, plants, and the world of nature.
- 9. Play. Being able to laugh, to play, to enjoy recreational activities.
- 10. Control over one's Environment.
 - C. Political. Being able to participate effectively in political choices that govern one's life; having the right of political participation, protection of free speech and association.
 - D. Material. Being able to hold property (both land and movable goods), and having property rights in an equal basis with others; having the right to seek employment on an equal basis with others; having the freedom of unwarranted search and seizure. In work, being able to work as a human being, exercising practical reason and entering into meaningful relationships of mutual recognition with other workers. (Nussbaum, 2006, p. 78).

Appendix Five
Tables on Autism and Social Support (Sub-themes)

Table 5.2 Mothers' Awareness about Their Sons' Different Behaviours

List of behaviours	Number of mothers in Saudi Arabia	Number of mothers in Bahrain
Sleeping disorders	Four (Nora, Amal, Rasha, Rana)	Four (Noor, Nouf, Maha, Warda)
Lack of communication	Four (Fatima, Amal, Nada, Rana)	Four (Samia, Noor, Nouf)
Unusual playing patterns	Seven (Sarah, Nora, Amal, Noha, Rasha, Nada, Rana)	
Loss of skills such as speaking and communication	Three (Huda, Rasha, Rana)	Four (Asma'a, Maha, Warda, Nouf)
Unusual crying patterns- crying too much or not crying at all	Six (Nora, Sarah, Amal, Rasha, Nada, Rana)	
Acted differently from their elder siblings	Six (Noha, Huda, Rasha, Mai, Nora, Rana)	
Prefers isolation	Five (Huda, Sarah, Nada, Mai, Rana)	One (Maha)
Severe hyperactivity and lack of attention	Three (Huda, Amal, Noha)	Two (Maha, Warda)
Making odd noises	Two (Noha, Mai)	Three (Sana'a, Noor, Nouf)
Does not play with his peers	Four (Huda, Nora, Amal, Noha)	
Does not realise the meaning of danger	Three (Huda, Noha, Rana)	
Unusual feeding patterns	Three (Nora, Sarah, Amal)	

List of behaviours	Number of mothers in Saudi Arabia	Number of mothers in Bahrain
Sensory issues- sensitive to light and sound	Three (Sarah, Rasha, Amal)	
Sudden behaviours such as laughing, shouting, and screaming for no obvious reason		Three (Sana'a, Noor, Nouf)
Destructive and aggression behaviour	Two (Huda, Amal)	
Unexplained fear of things and people		Two (Asma'a, Maha)
Non- verbal	Two (Fatima, Rana)	
Stiff facial expressions	One (Amal)	
Looking at the corner when feeding and lack of spontaneous smile		One (Samia)
Does not turn his head towards his parents when he is called		One (Noor)

Table 5.3 Mothers' Affective Responses toward Their Sons' Different Behaviours

Mothers' feelings	Number of mothers in Saudi Arabia	Numbers of mothers in Bahrain
Confusion	Nine (Fatima, Huda, Nora, Sarah, Amal, Noha, Rasha, Mai and Rana)	Four (Asma'a, Samia, Noor, Warda)
Feelings that their sons have a problem, although told otherwise	Two (Nada, Sarah)	Three (Sana'a, Noor, Maha)
Loneliness	Two (Rana, Nora)	
Sadness	Two (Fatima, Nora)	
Fear and denial	One (Nada)	
Guilt	One (Amal)	
Struggles and "going insane"	One (Rana)	

Table 5.4 Mothers' Interpretations of Their Sons' Behaviours

Mothers' interpretations	Numbers of mothers in Saudi Arabia	Numbers of mothers in Bahrain
Autism	One (Nada)	Three (Maha, Sana'a, Nouf)
Normal attachment behaviour	One (Amal)	
Hearing problems	One (Noha)	One (Samia)
Possession by some evil spirit	One (Rasha)	One (Warda)
Ali's jealousy from his new-born sister	One (Huda)	
Came cross autism through an internet search and noticed the similarities with her first son's behaviours. When she had her second son, and because of her experience with her first son, she knew he had autism	One (Rana)	
The helper was scaring her son	Mai	
Speech delay		One (Asma'a)
The rest of the Saudi mothers (Fatima, Nora, Sarah) did not have any interpretations		

Table 5.5 Mothers' Behavioural Responses toward Their Sons' Behaviours

Mothers' behavioural response	Number of mothers in Saudi Arabia
Seeking medical help from hospitals	Seven (Fatima, Nora, Amal, Noha, Nada, Mai, Rana, Sarah)
Seeking help in Autism Centres	Two (Huda, Rasha)
Seeking help in the work place	One (Sarah)
Praying to Allah for help	One (Fatima)
All mothers in Bahrain sought immediate medical help	

Table 5.6 The Misdiagnosis Phase

The diagnosis	Number of mothers in Saudi Arabia	Number of mothers in Bahrain
Received accurate diagnosis	Five (Fatima, Noha, Rasha, Nada, Rana)	Two (Asma'a, Samia)
ADHD	Three (Huda, Sarah, Amal)	
Separation anxiety disorder, and ADHD	One (Amal)	
Doctors were confused and could not manage a diagnosis until late	One (Nora)	
Intellectual disability	One (Mai)	One (Maha)
Hearing problems		Two (Sana'a, Noor)
Weird behaviours		One (Warda)
Nothing wrong with their sons		Two (Sana'a, Nouf)

Table 5.7 Mothers' Awareness of Autism

Mothers' awareness of autism	Number of mothers in Saudi Arabia	Number of mothers in Bahrain
Came across autism (online-television) and connect it to the son's behaviours	One (Rana)	Five (Asma'a, Sana'a, Samia, Maha, Nouf)
Never heard about autism	Five (Fatima, Huda, Nora, Noha, Mai)	
Familiar with autism since she is working in an Autism Centre	One (Nada)	
Heard about autism , but did not connect it to their sons' behaviours	Two (Amal, Sarah)	Two (Warda, Noor)
Heard about autism from neighbours and relatives	One (Rasha)	

Table 5.8 Mothers' Affective Responses toward Autism

Mothers' feelings	Numbers of mothers in Saudi Arabia	Number of mothers in Bahrain
Shock and lost	Three (Huda, Noha, Rana)	Three (Noor, Nouf, Samia)
Relief	three (Sarah, Mai, Nada)	Two (Asma'a, Maha)
Helpless	Two (Huda, Nora)	
Confusion	Two (Fatima, Huda)	
Painful and loneliness	Two (Amal, Rasha)	
Self- blame and frustration	One (Huda)	
Sadness	One (Nora)	
Hopelessness	One (Huda)	
Happiness		One (Sana'a)
Dismissed all feelings		One (Warda)

Table 5.9 Mothers' Behavioural Responses toward Autism

Mothers' behavioural response	Number of mothers in Saudi Arabia	Number of mothers in Bahrain
Use alternative methods	Eight (Huda, Nora, Amal, Noha, Mai, Rana, Rasha, Nada)	Four (Noor, Nouf, Asma'a, Sana'a)
Reading books and articles on the internet to educate themselves about autism and to try to understand their sons' behaviours	Five (Huda, Sarah, Amal, Rana, Noha)	Five (Asma'a, Samia, Noor, Warda, Nouf)
looking for public schools specialising in children with disabilities	Two (Fatima, Nora)	All mothers
Attend lectures and workshops on autism, to learn how to teach and treat their sons	Two (Sarah, Rana)	Two (Asma'a, Noor)

Mothers' behavioural response	Number of mothers in Saudi Arabia	Number of mothers in Bahrain
Enrolled their sons into Autism Centres immediately after the diagnosis	Two (Mai, Sarah)	
Decide to live in isolation with her son	Two (Rana, Amal)	
Resort to prayer	One (Nora)	
Volunteered in an Autism Centre to learn how to teach and treat her son	One (Rana)	

Table 5.10 Mothers' Awareness of the Adolescence Stage

Mothers' awareness	Number of mothers in Saudi Arabia	Number of mothers in Bahrain
Inappropriate sexual behaviour such as, touching oneself, sleeping on the tummy, touching others and touching oneself in public	Four (Rana, Sarah, Noha, Nada)	Four (Asma'a, Samia, Warda, Nouf)
Stubbornness, their sons do not listen to their mothers the way they used to	Five (Fatima, Huda, Sarah, Amal, Rana)	One (Samia)
Did not reach puberty	Three (Fatima, Amal, Nada)	One (Noor)
Trying to break the rules by arguing, shouting and crying	Four (Rana, Sarah, Amal, Nada)	
Became quieter	One (Huda)	Three (Sana'a, Maha, Nouf)
Developed epilepsy		Three (Maha, Asma'a, Samia)
Became more sensitive with age, and start taking everything personally	Three (Huda, Rana, Amal)	
Wet dreams		One (Sana'a)
Increased care about appearances	One (Mai)	One (Maha)
Masturbation		One (Nouf)
Prefers isolation	One (Amal)	One (Warda)

Table 5.11 Mothers' Affective Responses toward the Adolescence Stage

Mothers' feelings	Number of mothers in Saudi Arabia	Numbers of mothers in Bahrain
Acceptance		Four (Maha, Samia, Nouf, Warda)
Confused	One (Rasha)	One (Maha)
Hoping my son does not show sexual feelings/ behaviours	One (Mai)	One (Sana'a)
Better	Two (Noha, Rana)	
Natural		One (Asma'a)
Helpless		One (Maha)
Exhaustion	One (Amal)	
Scared	One (Rasha)	
Embarrassed and shy	One (Rasha)	

Table 5.12 Mothers' Behavioural Responses toward the Adolescence Stage

Mothers' behavioural responses	Number of mothers in Saudi Arabia	Number of mothers in Bahrain
Help their sons with showering and shaving sensitive areas	Five (Nora, Fatima, Rasha, Amal, Mai)	Three (Asma'a, Sana'a, Nouf)
Teach their sons independence	Two (Huda, Noha)	Three (Asma'a, Sana'a, Nouf)
Divert their sons' attention from sexual behaviour	Three (Nada, Noha, Rana)	One (Samia)
Issues with their son spending more time using electronics	Three (Rana, Sarah, Nada)	
Teach their sons privacy		Two (Asma'a, Nouf)
Sons are in boarding schools in Jordan		Two (Maha, Warda)
Avoid talk about puberty and sexual behaviour		One (Sana'a)
Resort to prayer		One (Maha)
Give their sons space and freedom	One (Sarah)	

Table 6.2 Spouse Support - Negative

Negative behaviour		
	Number of mothers in Saudi Arabia	Number of mothers in Bahrain
Completely withdrawn from the adolescent's life	Four (Nora, Sarah, Amal, Rasha)	One (Warda)
Controlling	Four (Fatima, Nora, Nada, Rasha)	
Does not visit the son's school	Four (Amal, Nada, Mai, Rana)	
Lack of support during the diagnosis	Three (Rasha, Mai, Rana)	One (Maha)
Lack of financial support	Two (Fatima, Nora)	One (Maha)
Blames the mother for the disorder	Two (Amal, Rana)	One (Maha)
Impatient with the adolescent	Two (Sarah, Amal)	One (Warda)
Not involved in the direct physical care of the child	Three (Noha, Mai, Rana)	
Lacks care	Three (Nora, Amal, Rana)	
Abusive	Two (Fatima, Nora)	
Lack of intimacy with the wife	Two (Amal, Rana)	
Does not accept the adolescent's condition	One (Rana)	One (Maha)
Does not provide mobility	One (Nora)	
Close minded and traditional	One (Rana)	

Negative behaviour		
	Number of mothers in Saudi Arabia	Number of mothers in Bahrain
Does not provide consent necessary for official institutes (Male guardianship law)	One (Nora)	
Feels embarrassed by his son	One (Rana)	
Unfaithful	One (Nora)	
Talks about having a second wife	One (Rana)	
Does not have a connection with his son		One (Warda)

Table 6.3 Spouse Support - Positive

Positive behaviour		
	Number of mothers in Saudi Arabia	Number of mothers in Bahrain
Fully supports the mother		Four (Asma'a, Samia, Noor, Nouf)
Shows care occasionally	Four (Sarah, Rana, Noha, Mai)	
Takes part in making decisions and support mother's decisions	One (Noha)	Two (Samia, Noor)
Take part in the direct physical care of the adolescent		Three (Asma'a, Sana'a, Nouf)
Attend hospital appointments and attending parents meetings and school workshops	Two (Huda, Noha)	
Not supportive at the beginning, became supportive after the diagnosis	One (Huda)	One (Sana'a)
Cares about his wife's comfort		One (Noor)
Provides mobility		One (Asma'a)
Pressured by his colleagues so they would care for his son	One (Huda)	
Takes full financial responsibility	One (Huda)	

Positive behaviour		
	Number of mothers in Saudi Arabia	Number of mothers in Bahrain
Proud of his adolescent	One (Huda)	
Forms a father-son connection	One (Huda)	

Table 6.4 Mothers' Affective Responses toward Their Spouse's Behaviour

Mothers' feelings	Number of mothers in Saudi Arabia	Numbers of mothers in Bahrain
Lonely	Four (Huda, Amal, Rasha, Nora)	
Mothers believe that Saudi men are not supportive by nature	Four (Amal, Rasha, Rana, Nada)	
Understand the limitation of the father/ Mother rationalises the father's behaviour	Two (Rasha, Nada)	One (Samia)
Hurt/upset/depressed	Two (Nora, Sarah)	
Blamed	Three (Rasha, Sarah, Huda)	
Mother rationalises the father's behaviour		One (Warda)
Grateful		One (Asma'a)
Depressed	One (Mai)	
Mother prefers father's lack of involvement	One (Sarah)	
Strong		One (Maha)

Table 6.5 Mothers' Behavioural Responses toward Their Spouse's Behaviour

Mothers' behavioural responses	Number of mothers in Saudi Arabia	Number of mothers in Bahrain
Try to make the relationship between the father and the son stronger despite the father's withdrawal	One (Amal)	One (Maha)
Prayers	One (Fatima)	
Mother goes to court to seek a legal solution	One (Fatima)	

Table 6.6 Family, Friends and Neighbours Support (Positive and Negative)

Family support	Number of mothers in Saudi Arabia	Number of mothers in Bahrain
Supportive siblings	Seven (Huda, Nora, Sarah, Noha, Nada, Mai, Rana)	Four (Asma'a, Sana'a, Noor, Warda)
Supportive Family		Five (Asma'a, Sana'a, Samia, Noor, Maha)
Family lack of support	Three (Amal, Mai, Rana)	Two (Warda, Nouf)
Unsupportive siblings	Four (Fatima, Amal, Rasha, Mai)	
Family denial	Two (Sarah, Nada)	Two (Noor, Maha)
Family struggle	One (Rasha)	Two (Warda, Nouf)
Financial support	Two (Fatima, Nora)	
Family acceptance	Two (Noha, Rana)	
Family's influence	Two (Sarah, Rasha)	
Family lack of acceptance		One (Maha)
Family avoidance	One (Huda)	
Friends support		
Supportive friends	One (Huda)	Two (Noor, Warda)
Neighbours support		
Supportive neighbours	One (Nora)	

Family support	Number of mothers in Saudi Arabia	Number of mothers in Bahrain
Neighbours taking advantage	One (Nora)	
Nanny support		
Supportive nanny	One (Sarah)	Two (Samia, Warda)
Driver support		
Supportive driver	One (Sarah)	

Table 6.7 Hospital Support (Positive and Negative)

Hospital support	Number of mothers in Saudi Arabia	Number of mothers in Bahrain
Failed to obtain a diagnoses	Five (Nora, Rasha, Amal, Nada, Rana)	Five (Sana'a, Noor, Maha, Warda, Nouf)
Lack care	One (Rasha)	Three (Noor, Warda, Nouf)
Provide helpful information	One (Rana)	Three (Asma'a, Samia, Noor)
Lack of information about the disorder at the time of the diagnoses	Two (Fatima, Noha)	One (Nouf)
Diagnoses abroad	One (Amal)	Three (Maha, Warda, Nouf)
Hospital was not involved in making a diagnoses	Two (Huda, Sarah)	
Public and privet hospitals		One (Sana'a)
Delayed appointments	One (Nada)	
Medical mistake	One (Nora)	
Medical procedures	One (Rana)	
Medication	One (Rana)	

Table 6.8 Schools- Autism Centres Support (Positive and Negative)

Schools support	Number of mothers in Saudi Arabia	Number of mothers in Bahrain
School issues	Nine (Huda, Nora, Sarah, Amal, Noha, Rasha, Nada, Mai, Rana)	Two (Warda, Nouf)
Lack care	Six (Fatima, Huda, Rasha, Nada, Mai, Rana)	Three (Asma'a, Samia, Warda)
Centre- School played a big role in the improvement of the adolescent	Four (Huda, Sarah, Mai, Rana)	Four (Asma'a, Maha, Warda, Nouf)
Schools rules and regulations (Male guardianship law)	Six (Fatima, Rana, Nora, Amal, Nada, Mai)	
Provide helpful information	Two (Huda, Mai)	Three (Asma'a, Sana'a, Noor)
Uncooperative with the mother	Five (Fatima, Nora, Noha, Rasha, Nada)	
Supportive centre	One (Rana)	Four (Samia, Noor, Maha, Nouf)
Adolescent staying at home - no school	Four (Fatima, Amal, Rasha, Mai)	
Studying abroad	Two (Noha, Nada)	Two (Maha, Warda)
Financial resources, private centres and mobility	Three (Fatima, Nora, Rasha)	
Lack of information about the disorder at the time of the diagnoses	Two (Huda, Mai)	
Integration	One (Huda)	One (Noor)
Not sharing the adolescent's condition with the school	One (Sarah)	

Schools support	Number of mothers in Saudi Arabia	Number of mothers in Bahrain
Overcome school rules	One (Amal)	
Move to Bahrain from Saudi Arabia to find better services		One (Samia)
Lack information	One (Mai)	
Centre focused on the strength of the adolescent	One (Mai)	One (Asma's)
Centre was not cooperatives at the beginning, then start supporting the mother	One (Huda)	

Table 6.9 Societal Support

Societal support	Number of mothers in Saudi Arabia	Number of mothers in Bahrain
Others' reactions to autism	Six (Huda, Nora, Sarah, Amal, Noha, Mai)	Five (Asma'a, Sana'a, Samia, Noor, Maha)
Rules and regulations	Seven (Fatima, Huda, Nora, Sarah, Rasha, Nada, Mai)	Four (Asma'a, Sana'a, Samia, Maha)
Awareness	Four (Noha, Nada, Mai, Rana)	Six (Asma'a, Samia, Noor, Maha, Warda, Nouf)
Social networks	Three (Fatima, Sarah, Amal)	Five (Asma'a, Samia, Noor, Maha, Warda)
Mothers' opinion of society	Three (Sarah, Amal, Nada)	Two (Samia, Maha)
Lack of understanding	Two (Mai, Amal)	Two (Asma'a, Warda)